Hallett, Mark (NIH/NINDS) [E]

To:

Koroshetz, Walter (NIH/NINDS) IEI: NINDS Press Team RE: reporter seeks interview for article in NY Times Magazine

Subject: Date:

Thursday, August 16, 2018 7:17:22 PM

Thanks, Walter. Two points.

(b) (5), (b) (6)

Second, Dan says he wants only to talk with me about functional neurological disorders in general and not about Cuba (although the article will be about Cuba). IN any event, I will do what I am told......mark

Mark Hallett, M.D., D.M.(hon)
Chief, Human Motor Control Section, NINDS-NIH, Building 10, Room 7D37
10 Center Dr MSC 1428
Bethesda, MD 20892-1428

Tel: 301-496-9526 Fax: 301-480-2286

email: hallettm@ninds.nih.gov

http://intra.ninds.nih.gov/Lab.asp?Org\_ID=72

From: Koroshetz, Walter (NIH/NINDS) [E] Sent: Thursday, August 16, 2018 6:32 PM

To: Hallett, Mark (NIH/NINDS) [E] <hallettm@ninds.nih.gov>; NINDS Press Team

<NINDSPressTeam@ninds.nih.gov>

Subject: RE: reporter seeks interview for article in NY Times Magazine

(b) (5), (b) (6)

walter

From: Hallett, Mark (NIH/NINDS) [E]
Sent: Monday, August.13, 2018 8:48 PM

To: NINDS Press Team < NINDSPressTeam@ninds.nih.gov>

Cc: Koroshetz, Walter (NIH/NINDS) [E] < koroshetzw@ninds.nih.gov > Subject: FW: reporter seeks interview for article in NY Times Magazine

Dear Press Team,

As you see below, Dan Hurley will be writing you asking for permission to talk with me about functional neurological disorders in an article that he is planning about the Cuban diplomats. I tried to turn him down, but he is persistent. You can decide whether it is appropriate. If I do talk with him, I would stay strictly away from Cuba and talk only about the disorder in general. However, even this might be considered inappropriate at this point in time.

(b) (5), (b) (6)

In any event, this is a very

sensitive issue, again as you likely know, so any interview should be approved by HHS at highest level. I will copy Walter Koroshetz to keep him in the loop too......mark

From: Dan Hurley [mailto:hurleydan1@gmail.com]

Sent: Monday, August 13, 2018 8:26 PM

To: Hallett, Mark (NIH/NINDS) [E] < hallettm@ninds.nih.gov>

Subject: Re: reporter seeks interview for article in NY Times Magazine

Hi Mark: Thanks for your reply last week. I was away in Vermont. I appreciate your concern that the NIH press office might not want you to discuss this topic. As a leading scientist who has published dozens of articles on functional neurological disorders, you are in an excellent position to discuss the general topic. Your position as chief of the Human Motor Control Section at NINDS lends your views particular weight. In over 25 years as a medical reporter specializing in neurology, I can't recall a single time that the NIH press office refused a request for an interview with a scientist on his or her area of specialty. I am happy to respect any conditions or concerns you or the press office might have. I'm certainly not trying to get you in trouble. Almost every article I write ends up quoting docs with different points of view. That's how both science and journalism work. So.... would you mind if I reach out to the NINDS press office, to ask their permission to speak with you? Thanks, Dan

On Mon, Aug 6, 2018 at 6:35 PM, Hallett, Mark (NIH/NINDS) [E] < hallettm@ninds.nih.gov> wrote:

Hi Dan,

The NIH is concerned about us in HHS getting involved with matters of the State Department. While I originally helped Jon Stone with the letter to JAMA, the NIH did not want me to sign on, so I do not know what its final form was. I agree that I-have not heard that it was published. So I suspect that it is unlikely that NIH (HHS) will allow an interview of me on this topic as the article is focused on the Cuban problem. I apologize that I cannot help you. I am sure, however, that you can find many other experts in the USA who could provide you the information and points of view that you are seeking.

Mark

Mark Hallett, M.D., D.M.(hon)
Chief, Human Motor Control Section, NINDS
NIH, Building 10, Room 7D37
10 Center Dr MSC 1428
Bethesda, MD 20892-1428

Tel: 301-496-9526 Fax: 301-480-2286

email: hallettm@ninds.nih.gov

http://intra.ninds.nih.gov/Lab.asp?Org\_ID=72

From: Dan Hurley [mailto:hurleydan1@gmail.com]

Sent: Monday, August 06, 2018 6:16 PM

To: Hallett, Mark (NIH/NINDS) [E] < hallettm@ninds.nih.gov>
Subject: reporter seeks interview for article in NY Times Magazine

Hi Dr. Hallett: I'm a science reporter specializing in neurology topics, and wrote an article in

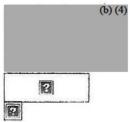
February for Neurology Today about the US diplomats in Cuba who have experienced a variety of symptoms, including dizziness, after hearing unusual sounds. I interviewed Jon Stone for that article, who mentioned that you had coauthored with him and others a letter submitted to JAMA making the case that the symptoms were likely functional, rather than due to a "sonic attack." (I don't believe that JAMA ever published the letter?)

I am now writing a longer article for the New York Times Magazine about this ongoing question of what has caused the diplomats' symptoms, and the broader subject of just how powerful (and misunderstood) functional disorders can be. I've looked over some of your fascinating studies on functional movement disorders.

I would very much like to interview you about this subject. Is there a good time when we might talk by telephone in the next week or two? Thanks very much, Dan Hurley

From: To:	Hallett, Mark (NIH/NINDS) [E]			
Subject:	RE: A short media request from (b) (4)			
Date:	Tuesday, March 13, 2018 11:44:26 AM			
NIH will not	allow this. Sorry.			
Mark Hallet	t,.M.D., D.M.(hon)			
	an Motor Control Section, NINDS			
NIH, Buildin	ig 10, Room 7D37			
10 Center D	or MSC 1428			
Bethesda, N	ND 20892-1428			
Tel: 301-496	6-9526			
Fax: 301-48	80-2286			
email: halle	ttm@ninds.nih.gov			
http://intra	ninds;nih.gov/Lab.asp?Org_ID=72			
From:		(b) (4)		
Sent: Tuesd	lay, March 13, 2018 11:41 AM			
To: Hallett,	Mark (NIH/NINDS) [E] <hallettm@nind< td=""><td>s.nih.gov&gt;</td><td></td><td></td></hallettm@nind<>	s.nih.gov>		
Subject: A s	short media request from (b) (4)			
Dear Dr. Ha	llet,			
I hope this e	email finds you well. My name is	(b) (4) and I'm the		producer for 1) I am writing to
invite you to	be part of our show.			7 7 4 17 17 18 10
Cuba. And v	ently producing a report on the alleged swe are interested in getting a medical per n discussing our brain's susceptibility to a	rspective from you on the	subject. W	
Ideally, we v	would like to schedule the interview some ility?	etime this week as soon a		Might you have We could also
bring a cam	era to your offices if that is more conveni	ent.		
	ew would be a short, on-camera commenuced piece. The whole process, including			
I am happy reached any	to answer any questions you may have a (b) (4) or by e-mail at	about our show or the ang	gle of the st	ory. I can be
Thank you i	in advance for your time and interest.			
All best,				
(b) (4)				





Thomas, Christopher (NIH/NINDS) [E]

To:

Hallett, Mark (NIH/NINDS) [E]

Subject:

RE: PRESS REQUEST: Surgery for Neurological Conditions Monday, March 12, 2018 10:40:00 AM

Attachments:

image001.png

Hi Mark,

HHS has approved the interview.

Best, Chris

From:

(b) (4)

Sent: Sunday, March 11, 2018 4:11 PM

To: Hallett, Mark (NIH/NINDS) [E] <hallettm@ninds.nih.gov>
Cc: NINDS Press Team <NINDSPressTeam@ninds.nih.gov>

Subject: Re: PRESS REQUEST: Surgery for Neurological Conditions

Thank you! My editor identified you for DBS. It would be great if you can speak to FUS as well, assuming the Press Office agrees.

Please keep me posted.

(b) (4)

From: "Hallett, Mark (NIH/NINDS) [E]" < hallettm@ninds.nih.gov>

Date: Sunday, March 11, 2018 at 7:13 AM

Cc: NINDS Press Team < NINDSPressTeam@ninds.nih.gov>

Subject: RE: PRESS REQUEST: Surgery for Neurological Conditions

I would not consider myself a real expert, but I could respond about DBS and FUS to some extent. In any event, I am not permitted to do this unless I get permission from NIH. I will copy the Press Office and see if this will work..............

Mark Hallett, M.D., D.M.(hon)
Chief, Human Motor Control Section, NINDS
NIH, Building 10, Room 7D37
10 Center Dr MSC 1428
Bethesda, MD 20892-1428

Tel: 301-496-9526 Fax: 301-480-2286

email: halleum@ninds.nih.gov

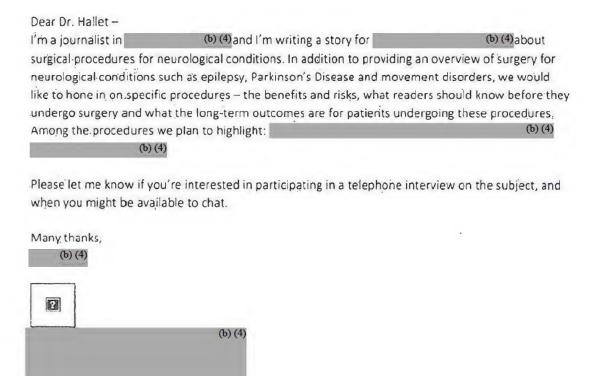
http://intra.ninds.nih.gov/Lab.asp?Org\_ID=72

From: (b) (4)

Sent: Sunday, March 11, 2018 1:36 AM

To: Hallett, Mark (NIH/NINDS) [E] < hallettm@ninds.nih.gov>

Subject: PRESS REQUEST: Surgery for Neurological Conditions



From: To: Hallett, Mark (NIH/NINDS) [E]

Thomas, Christopher (NIH/NINDS) [E]

Subject:

RE: Invitation to participate in a neurology podcast

Date:

Friday, March 9, 2018 4:53:33 PM

### thanks

Mark Hallett, M.D., D.M.(hon) Chief, Human Motor Control Section, NINDS NIH, Building 10, Room 7D37 10 Center Dr.MSC 1428 Bethesda, MD 20892-1428

Tel: 301-496-9526 Fax: 301-480-2286

email: hallenm@ninds.nih.gov

http://intra.ninds.nih.gov/Lab.asp?Org\_ID=72

From: Thomas, Christopher (NIH/NINDS) [E] Sent: Friday, March 09, 2018 1:39 P.M

To: Hallett, Mark (NIH/NINDS) [E] <hallettm@ninds.nih.gov>Subject: RE: Invitation to participate in a neurology podcast

Hi Mark,

HHS approved the interview.

Best, Chris

From: Hallett, Mark (NIH/NINDS) [E]
Sent: Thursday, March 08, 2018 9:13 PM

To: NINDS Press Team < NINDSPressTeam@ninds.nih.gov>
Subject: FW: Invitation to participate in a neurology podcast

Is this okay? Thanks.....mark

From:

(b) (4)

Sent: Thursday, March 08, 2018 7:25 PM

To: Hallett, Mark (NIH/NINDS) [E] < hallettm@ninds.nih.gov>
Subject: Re: Invitation to participate in a neurology podcast

Hi Dr. Hallett,

I apologize for a second email. I hope you will consider this interview as part of this educational program I have built for medical trainees.

Thank you.

	(b) (4)
n Sun, Feb 11, 2018 at 5:18 PM,	(b) (4) <sub>wrote</sub> :
Hi Dr. Hallett,	
My name is (b) (4) and I am th	ne Producer of the (b) (4) and the NIH
wy hame is corto and rain th	(b) (4). I am writing to you in regard
to an upcoming episode of the MRI in conversion disorder.	(b) (4) podcast which will focus broadly on the subject of
program that can be accessed on it	e program. Briefly, the (b) (4) podcast is a (b) (4) audio Tunes, GooglePlay, Stitcher, and a variety of other media, and
our episodes are downloaded 6-8,0 fellows, as well as practicing physic	Tunes, GooglePlay, Stitcher, and a variety of other media, and 000 times per month by medical students, residents and
our episodes are downloaded 6-8,0 fellows, as well as practicing physic episodes, with over 60 (4) unique.  This April 1st, I plan to release a shidisorder and other disorders of sor	Tunes, GooglePlay, Stitcher, and a variety of other media, and 2000 times per month by medical students, residents and cians around the world. To date, we have published over (b) (4) to downloads.  Ow concurrent with the theme of April Fool's Day. Conversion matization have always interested me, and I think this would be incess on functional imaging, and in particular, how fMRI may
our episodes are downloaded 6-8,0 fellows, as well as practicing physic episodes, with over (b) (4) unique. This April 1st, I plan to release a she disorder and other disorders of sor a great opportunity to educate trainform us about psychosomatic distince you will consider participating.	Tunes, GooglePlay, Stitcher, and a variety of other media, and 2000 times per month by medical students, residents and cians around the world. To date, we have published over (b) (4) to downloads.  Ow concurrent with the theme of April Fool's Day. Conversion matization have always interested me, and I think this would be incess on functional imaging, and in particular, how fMRI may
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our episodes are downloaded 6-8,0 fellows, as well as practicing physic episodes, with over (b) (4) unique. This April 1st, I plan to release a shi disorder and other disorders of sor a great opportunity to educate trainform us about psychosomatic distribution in the properticipation of the pr	Tunes, GooglePlay, Stitcher, and a variety of other media, and 2000 times per month by medical students, residents and cians around the world. To date, we have published over (b) (4) the downloads.  Ow concurrent with the theme of April Fool's Day. Conversion matization have always interested me, and I think this would be inceed on functional imaging, and in particular, how fMRI may corders.  Ing in this interview. Typically, interviews are conducted over pondents are provided with the questions well in advance.

Hallett, Mark (NIH/NINDS) [E]

To:

Thomas, Christopher (NIH/NINDS) [E]

Subject: Date:

RE: (b) (4) Interview Topics

Monday, February 26, 2018 8:59:41 PM

ok

Mark Hallett, M.D., D.M.(hon) Chief, Human Motor Control Section, NINDS NIH, Building 10, Room 7D37 10 Center Dr MSC 1428 Bethesda, MD-20892-1428

Tel: 301-496-9526 Fax: 301-480-2286

email: hallettm@ninds.nih.gov

http://intra.ninds.nih.gov/Lab.asp?Org\_ID=72

From: Thomas, Christopher (NIH/NINDS) [E] Sent: Monday, February 26, 2018 3:40 PM

To: Hallett, Mark (NIH/NINDS) [E] <hallettm@ninds.nih.gov>

Subject: RE: (b) (4) Interview Topics

Hi Mark,

The reporter canceled this week's interview. She may be in the DC area next week. I'll let you know

more. Best, Chris

From: Hallett, Mark (NIH/NINDS) [E]

Sent: Friday, February 23, 2018 11:46 AM

:To: Thomas, Christopher (NIH/NINDS) [E] < christopher.thomas@nih.gov>

Subject: RE: (b) (4) Interview Topics

OK. The expert in NYC is Dr. Stan Fahn at Columbia. 'He is the father of the whole movement

disorder field and this is one of his interests.....mark

Mark Hallett, M.D., D.M.(hon) Chief, Human Motor Control Section, NINDS NIH, Building 10, Room 7D37 10 Center Dr MSC 1428 Bethesda, MD 20892-1428

Tel: 301-496-9526

Fax: 301-480-2286

email: hallettm@ninds.nih.gov

http://intra.ninds.nih.gov/Lab.asp?Org ID=72

From: Thomas, Christopher (NIH/NINDS) [E] Sent: Friday, February 23, 2018 11:37 AM To: Hallett, Mark (NIH/NINDS) [E] < hallettm@ninds.nih.gov> Subject: (b) (4) Interview Topics Hi Mark, Below are the topics the (b) (4) reporter would like to cover with you. Is there an expert FND expert in the New York City area? Best, Chris From: (b) (4) Sent: Wednesday, February 21, 2018 4:34 PM To: Thomas, Christopher (NIH/NINDS) [E] < <a href="mailto:christopher.thomas@nih.gov">christopher.thomas@nih.gov</a> Subject: Re: Cuba query. Dear Chris, Per our call, here are two pieces we'd ask Dr. Hallett to comment on: (b)(4)

We're also hoping for a basic explanation of mass hysteria, and maybe some instances of when it's appeared to happen. We'd also be curious in terms of medical sleuthing how one might go about concluding this phenomena took place, and the challenges of figuring out mystery illnesses in general.

Thank you,

(b) (4)

Thomas, Christopher (NIH/NINDS) [E]

To:

Hallett. Mark (NIH/NINDS) [E]

Subject:

Talk w/ (b) (4)about Cuba?

Date:

Friday, February 16, 2018 12:41:00 PM

Hi Mark,

Next week, would you be willing to be interviewed on camera by the

(b) (4) about neurological

problems reported by the U.S. diplomats in Cuba (see email below)?

If so, when would you be free and is there some time today we could chat over the phone about it? I'm working from home today. So feel free to call my cell phone or ask me to call.

Thanks,

Chris Cell:

(b) (6)

Christopher G. Thomas, Ph.D.

Science Writer, Press Team Lead

Office of Communications and Public Liaison

National Institute of Neurological Disorders & Stroke

National Institutes of Health

Building 31, Room 8A07

31 Center Drive MSC 2510

Bethesda, MD 20892-2510

Phone: (301) 435-2264 Fax: (301) 402-2186

Email: thomaschr@ninds.nih.gov

From:

Sent: Tuesday, February 13, 2018:12:04 PM

To: Wojtowicz, Emma (NIH/OD) [E] < emma.wojtowicz@nih.gov>

Subject: Cuba query.

Hi Emma,

Per our chat just now, I'm with the video team and we're working on a documentary on US-Cuba relations, one part of which looks at the American diplomats impacted (some say attack, some say not), and I know, for example, that Dr. Mark Hallett has talked about the mass hysteria aspect of this before. We also know that another possibility discussed has been a 60 (4) type of situation. Is anyone at NIH able to discuss this in any way?

In terms of deadline, we're actually in DC next week, so if someone is available then, that would be fantastic.

Let me know and thank you,

(b)(4)

(b) (4

į

1

Alter, Katharine (NIH/CC/PDB) [E]

To:

Hallett, Mark (NIH/NINDS) [E]; Ehrlich, Debra (NIH/NINDS) [E]; Karp, Barbara (NIH/NINDS) [E]; Freimuth, Molly

(NIH/CC/OC) [E]: NINDS Press Team

Cc:

Nath, Avindra (NIH/NINDS) [E]: Ahmad, Omar (NIH/NINDS) [E]

Subject:

RE: FYI Interview request: Dystonia and the use of Botulinum Toxin/Botox

Date: Thursday, January 18, 2018 5:57:29 PM

OK

From: Hallett, Mark (NIH/NINDS) [E]

Sent: Thursday, January 18, 2018 5:51 PM

To: Alter, Katharine (NIH/CC/PDB) [E] <kalter@cc.nih.gov>; Ehrlich, Debra (NIH/NINDS) [E] <debra.ehrlich@nih.gov>; Karp, Barbara (NIH/NINDS) [E] <karpb@ninds.nih.gov>; Freimuth, Molly (NIH/CC/OC) [E] <molly.freimuth@nih.gov>; NINDS Press Team <NINDSPressTeam@ninds.nih.gov> Cc: Nath, Avindra (NIH/NINDS) [E] <avindra.nath@nih.gov>; Ahmad, Omar (NIH/NINDS) [E]

<omar.ahmad@nih.gov>

Subject: RE: FYI Interview request: Dystonia and the use of Botulinum Toxin/Botox

Thanks, you should just go ahead unless NINDS would like to have someone from NINDS participate.....mark

Mark Hallett, M.D., D.M.(hon) Chief, Human Motor Control Section, NINDS NIH, Building 10, Room 7037 10 Center Dr MSC 1428 Bethesda, MD 20892-1428

Tel: 301-496-9526 Fax: 301-480-2286

email: hallettm@ninds,nih.gov

http://intra.ninds.nih.gov/Lab.asp?Org ID=72

From: Alter, Katharine (NIH/CC/PDB) [E] Sent: Thursday, January 18, 2018 1:19 PM

To: Ehrlich, Debra (NIH/NINDS) [E] <debra.ehrlich@nih.gov>; Karp, Barbara (NIH/NINDS) [E] <karpb@ninds.nih.gov>; Hallett, Mark (NIH/NINDS) [E] <hallettm@ninds.nih.gov>; Freimuth, Molly (NIH/CC/OC) [E] <molly.freimuth@nih.gov>; NINDS Press Team <ninds.nih.gov> Cc: Nath, Avindra (NIH/NINDS) [E] <a href="mailto:avindra.nath@nih.gov">avindra.nath@nih.gov</a>; Ahmad, Omar (NIH/NINDS) [E] <a href="mailto:avindra.nath@nih.gov">avindra.nath@nih.gov</a>; Ahmad, Omar (NIH/NINDS) [E] <a href="mailto:avindra.nath@nih.gov">avindra.nath@nih.gov</a>

Subject: RE: FYI Interview request: Dystonia and the use of Botulinum Toxin/Botox

Mark et al,

I am fine handling this on my own but also happy to have someone from the NINDS there if you are interested in coming

#### Katharine

From: Ehrlich, Debra (NIH/NINDS) [E]

Sent: Thursday, January 18, 2018 8:29 AM

To: Karp, Barbara (NIH/NINDS) [E] < karpb@ninds.nih.gov>; Hallett, Mark (NIH/NINDS) [E] < hallettm@ninds.nih.gov>; Freimuth, Molly (NIH/CC/OC) [E] < molly.freimuth@nih.gov>; NINDS Press Team < NINDSPressTeam@ninds.nih.gov>; Alter, Katharine (NIH/CC/PDB) [E] < kalter@cc.nih.gov>

Cc: Nath, Avindra (NIH/NINDS) [E] <a href="mailto:avindra.nath@nih.gov">avindra.nath@nih.gov</a>; Ahmad, Omar (NIH/NINDS) [E]

<omar.ahmad@nih.gov>

Subject: Re: FYI Interview request: Dystonia and the use of Botulinum Toxin/Botox

I am also in agreement. Happy to join if any additional help or support is desired, otherwise I'm also fine with Katharine doing it.

Best wishes,

Debra

Debra Ehrlich, MD
Chief, NIH Parkinson's Disease Clinic
National Institute of Neurological Disorders and Stroke, NIH
Building 10, Room 7D37
10 Center Drive, MSC 1428
Bethesda, MD 20892

Tel: 301-443-7888 Fax: 301-480-2286

From: "Karp, Barbara (NIH/NINDS) [E]" < karpb@ninds.nih.gov>

Date: Wednesday, January 17, 2018 at 8:59 PM

To: "Hallett, Mark (NIH/NINDS) [E]" < hallettm@ninds.nih.gov>; "Freimuth, Molly (NIH/CC/OC) [E]" < molly freimuth@nih.gov>, NINDS Press Team < NINDSPressTeam@ninds.nih.gov>, "Alter, Katharine (NIH/CC/PDB) [E]" < kalter@cc.nih.gov>

Cc: "Nath, Avindra (NIH/NINDS) [E]" <a href="mailto:swindra.nath@nih.gov">"Ehrlich, Debra (NIH/NINDS) [E]" <a href="mailto:debra.ehrlich@nih.gov">"Ahmad, Omar (NIH/NINDS) [E]" <o href="mailto:swind-and-mailto:s

Same for me. I am fine with Katharine handling it but would be willing to participate if she wants.

Barbara I. Karp, MD Chair, Combined NeuroScience IRB Bld 31; Room B2B32 National Institutes of Health 9000 Rockville Pike Bethesda, MD 20892

phone: 301-496-0150 fax: 301-480-2973

httP://neuroscience.nih.gov/irb

From: "Hallett, Mark (NIH/NINDS) [E]" < hallettm@ninds.nih.gov>

Date: Wednesday, January 17, 2018 at 6:17 PM

To: "Freimuth, Molly (NIH/CC/OC) [E]" < molly.freimuth@nih.gov>, NINDS Press Team

<NINDSPressTeam@ninds.nih.gov>

Cc: "Avindra Nath, [E]" <avindra.nath@nih.gov>, "Ehrlich, Debra (NIH/NINDS) [E]"

<a href="mailto:square;"><debra.ehrlich@nih.gov</a>, Barbara Karp <a href="mailto:karpb@ninds.nih.gov">karpb@ninds.nih.gov</a>, "Ahmad, Omar (NIH/NINDS)

[E]" <omar:ahmad@nih.gov>

Subject: RE: FYI Interview request: Dystonia and the use of Botulinum Toxin/Botox

Ok with me to just have Katharine do it. If she wants help from any of us, or if NINDS wants someone from NINDS to participate, I am sure we would be happy to participate. Mark

Mark Hallett, M.D., D.M.(hon)
Chief, Human Motor Control Section, NINDS
NIH, Building 10, Room 7D37
10 Center Dr MSC 1428
Bethesda, MD 20892-1428
Tel: 301-496-9526

Tel: 301-496-9526 Fax: 301-480-2286

email: hallettm@ninds.nih.gov

http://intra.ninds.nih.gov/Lab.asp?Org ID=72

From: Freimuth, Molly (NIH/CC/OC) [E]
Sent: Wednesday, January 17, 2018 2:46 PM

To: NINDS Press Team < NINDSPressTeam@ninds.nih.gov>

Cc: Hallett, Mark (NIH/NINDS) [E] < hallettm@ninds.nih.gov>; Nath, Avindra (NIH/NINDS) [E] < avindra.nath@nih.gov>; Ehrlich, Debra (NIH/NINDS) [E] < debra.ehrlich@nih.gov>; Karp, Barbara (NIH/NINDS) [E] < karpb@ninds.nih.gov>; Ahmad, Omar (NIH/NINDS) [E] < omar.ahmad@nih.gov> Subject: FYI Interview request: Dystonia and the use of Botulinum Toxin/Botox

## Good afternoon,

I wanted to flag a request that has come across our plate to speak with our researcher Dr. Katherine Alter, in the Rehabilitation Medicine Department.

More details are below, including the patient that referring the media outlet to Dr. Alter. The patient is on board, and I will work on getting his communications consent form. These are some of the trials he's been a part of:

https://clinicaltrials.gov/ct2/show/NCT01019343?term=10-N-0009&rank=1 https://clinicaltrials.gov/ct2/show/NCT00001208?term=85-N-0195&rank=1 https://clinicaltrials.gov/ct2/show/NCT00001367?term=93-N-0202&rank=1 Dr. Alter said of course, if anyone from NINDS wants to join the filming on Feb. 1, they should since it's a joint collaboration.

She mentioned the names of all of those cc'd - hence why I wanted to flag specifically to them.

Molly

Molly H. Freimuth, MBA
Media Lead
Office of Communications and Media Relations
National Institutes of Health Clinical Center
molly.freimuth@nih.gov
Office: 301-594-5789

Cell: (b) (6)

Reporter: (b) (4)

Organization: (b) (c)

Subject: Dystonia and the use of Botulinum Toxin/Botox

Spokesperson: Dr. Katherine, Alter, MD, Staff Clinician, NIH Clinical Center

Expected place of publication (print, online broadcast): broadcast

Expected date of publication/airing: TBD

Expected prominence, (e.g. front page, Sunday, evening/morning; show, etc.): low

Key messages/talking points:

Dr. Alter will answer questions about the patients specific condition/symptoms, treatment with Botulinum Toxin; and his current regimen (and the use of Botox) and she will describe what dystonia is and the use of botulinum toxin for patients, that have dystonia.

Additional information:

(b) (4)

Hallett, Mark (NIH/NINDS) [E]

To:

(b) (4) Thomas, Christopher (NIH/NINDS) [E]

Subject:

RE: NIH Interview: Mark Hallett-& functional neurological disorders

Date:

Fnday, January 12, 2018 7:25:35 PM

I could talk some time on Monday.....I am free all day......

Mark Hallett, M.D., D.M.(hon)
Chief, Human Motor Control Section, NINDS
NIH, Building 10, Rooin 7D37
10 Center Dr MSC 1428
Bethesda, MD 20892-1428

Tel: 301-496-9526 Fax: 301-480-2286

email: hallettm@ninds.nih.gov

http://intra.ninds.nih.gov/Lab.asp?Org ID=72

From:

(b) (4)

Sent: Friday, January 12, 2018 6:37 PM

To: Thomas, Christopher (NIH/NINDS) [E] <christopher:thomas@nih.gov>; Hallett, Mark (NIH/NINDS)

[E] <hallettm@ninds.nih.gov>

Subject: Re: NIH Interview: Mark Hallett & functional neurological disorders

Thanks so much, Chris! I really appreciate it.

Let me know a good time for you, Dr. Hallett. I assume you're out Monday, but Tuesday would be fine too.

Have a good weekend!

(b) (4)

Newsletter Website

Book

From: "Thomas, Christopher (NIH/NINDS) [E]" < christopher.thomas@nih.gov>

To: (b) (4), "Hallett, Mark (NIH/NINDS) [E]" <hallettm@ninds.nih.gov>

Sent: Friday, January 12, 2018 4:53 PM

Subject: NIH Interview: Mark Hallett & functional neurological disorders

Hi (b) (4

Dr. Hallett would be glad to talk with you about functional neurological disorders. To help schedule an interview, I've included him in this message.

Feel free to contact me if you have any further questions etc.

Good luck! Chris

Mark Hallett, M.D., senior investigator, NIH's National Institute of Neurological Disorders and Stroke

Email: hallettm@ninds.nih.gov Office Phone: 301-496-9526

(b) (4)

Christopher G. Thomas, Ph.D.
Science Writer, Press Team Lead
Office of Communications and Public Liaison
National Institute of Neurological Disorders & Stroke
National Institutes of Health
Building 31, Room 8A07

31 Center Drive MSC 2510 Bethesda, MD 20892-2510 Phone: (301) 435-2264 Fax: (301) 402-2186

Email: thomaschr@ninds.nih.gov

Thomas, Christopher (NIH/NINDS) [E]

To:

Hallett, Mark (NIH/NINDS) [E]

Subject:

RE: Talk w/ (b)Reporter about Functional Neurological Disorders?

Date:

Friday, January 12, 2018 5:47:00 PM

Hi Mark,

Great! HHS approved the interview. I assured them that you would strictly talk about functional neurological disorders and not about Cuba etc.

In a moment, I'll send you and the reporter an introductory email to help you schedule the interview.

Good luck!

Chris

From: Hallett, Mark (NIH/NINDS) [E] Sent: Friday, January 12, 2018 4:49 PM

To: Thomas, Christopher (NIH/NINDS) [E] <christopher.thomas@nih.gov>
Subject: RE: Talk w/ (b) (4)Reporter about Functional Neurological Disorders?

Sure, I would be willing to do it.....mark

Mark Hallett, M.D., D.M.(hon)
Chief, Human Motor Control Section, NINDS
NIH, Building 10, Room 7D37
10 Center Dr MSC 1428
Bethesda, MD 20892-1428
Tel: 301-496-9526

Fax: 301-480-2286

email: hallettm@ninds.nih.gov

http://intra.ninds.nih.gov/Lab.asp?Org ID=72

From: Thomas, Christopher (NIH/NINDS) [E] Sent: Friday, January 12, 2018 4:47 PM

To: Hallett, Mark (NIH/NINDS) [E] < hallettm@ninds.nih.gov>

Subject: Talk w/ (b) (4) Reporter about Functional Neurological Disorders?

Hi Mark,

A reporter from (b) (4) is interested speaking with an expert in functional neurological disorders (see below). As he says, it's in lieu of the Cuba hearing loss story but that he doesn't need someone to comment on that.

Would you be willing to talk with him? His deadline is early next week.

If not, do have a recommendation on another expert?

Best,

Chris

Christopher G. Thomas, Ph.D.

Science Writer, Press Team Lead
Office of Communications and Public Liaison
National Institute of Neurological Disorders & Stroke
National Institutes of Health
Building 31, Room 8A07
31 Center Drive MSC 2510
Bethesda, MD 20892-2510

Phone: (301) 435-2264 Fax: (301) 402-2186

From:

Email: thomaschr@ninds.nih.gov

Sent: Friday, January 12, 2018 4:38 PM	
To: Thomas, Christopher (NIH/NINDS) [E] < christopher.thomas@nih.gov>	
Subject: Re: Media Inquiry	
The story is nominally about the Cuba attacks, but I don't need anyone to com-	iment on that.
What I need is someone who can explain in more detail what functional neuro arewhat are the pathways, how do they work, how open to treatment are the framework different from the psychosomatic framework. That sort of thing.	
(b) (4) (4) (cultural syndromes, which are in the same category. I'm wanting to delve deep actual mechanism.	out about per into the
(b) (4)	
Newsletter Website Book	
DOOK .	*
From: (b) (4) Sent: Friday, January 12, 2018 10:34 AM	
To: NINDS Press Team < NINDSPressTeam@ninds.nih.gov> Subject: Media Inquiry	
Hello,	
I'm a writer for (b) (4) magazine, and	(b) (4
(b) (4) I wondering if would be possible to talk to	
about the finer points of functional neurologic disorders some time this	atternoon or

early next week. If so that would be very helpful.

Thanks much,

(b) (4)

Newsletter Website Book

From: Hallett, Mark (NIH/NINDS) [E]
Sent: 21 Oct 2018 19:45:30 +0000

To: Clare Wilson

Cc: NINDS Press Team; Finnell, Katy (NIH/NINDS) [E]; Hicks, Elizabeth (NIH/NINDS) [C]

Subject: RE: New Scientist article on functional neurological disorders

I can speak with you only after review of the situation by the NINDS Press Team, whom I have copied. If it will work, someone in my office will arrange the time with you......

Mark Hallett, MD, DM (hon)
Human Motor Control Section
Medical Neurology Branch
National Institute of Neurological Disorders and Stroke
National Institutes of Health
Building 10, Room 7D37
10 Center Drive

Bethesda, MD 20892-1428

Tel: 301-496-9526 Fax: 301-480-2286

Email: hallettm@ninds.nih.gov

From: Clare Wilson < Clare. Wilson@newscientist.com>

Sent: Saturday, October 20, 2018 6:32 AM

To: Hallett, Mark (NIH/NINDS) [E] <hallettm@ninds.nih.gov>

Subject: Re: New Scientist article on functional neurological disorders

Thanks for getting back to me and I'm sorry to have bothered you when you're travelling. Would there be a day after your travels when you might be able to spare 20 minutes or so please? I have spoken with several UK doctors so far (I am based in London) but it would be great to get a picture of treatment of FNDs in the US too.

Many thanks				
Clare				
Clare Wilson				
Medical reporter				

+44 (0)7880 785 499

+44 (0)20 8288 8363

www.newscientist.com

From: Hallett, Mark (NIH/NINDS) [E] < hallettm@ninds.nih.gov>

Sent: 20 October 2018 08:36

To: Clare Wilson

Subject: RE: New Scientist article on functional neurological disorders

Sorry (b) (6) through mid-next week.....

Mark Hallett, MD, DM (hon)
Human Motor Control Section
Medical Neurology Branch
National Institute of Neurological Disorders and Stroke
National Institutes of Health
Building 10, Room 7D37
10 Center Drive
Bethesda, MD 20892-1428

Tel: 301-496-9526 Fax: 301-480-2286

Email: hallettm@ninds.nih.gov

From: Clare Wilson < Clare. Wilson@newscientist.com >

Sent: Friday, October 19, 2018 4:50 AM

To: Hallett, Mark (NIH/NINDS) [E] < hallettm@ninds.nih.gov > Subject: New Scientist article on functional neurological disorders

Dear Dr Hallett - I'm a journalist at New Scientist magazine and I'm writing a feature-length article about functional neurological disorders. Do you have some time for a chat by phone about your work in this area please? If that's OK it would ideally need to be some time in the next few days, if possible,

Many thanks, in advance, if you're able to help.

Best wishes

Clare Wilson

## Clare Wilson

Medical reporter

New Scientist

+44 (0)7880 785 499

+44 (0)20 8288 8363

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 From:
 Gallagher, Alissa (NIH/NINDS) [E]

 Sent:
 29 Oct 2018 14:58:18 +0000

To: Koroshetz, Walter (NIH/NINDS) [E];Adams, Amy (NIH/NINDS) [E];Scott, Paul

(NIH/NINDS) [E]

Subject: NBC News article about embassy attacks

FYI, article in NBC News about the embassy attacks: <u>Evacuated after 'health attacks' in Cuba and China, diplomats face new ordeals in U.S.</u>

Thanks, Alissa



From: Hallett, Mark (NIH/NINDS) [E]

Sent: Tuesday, September 11, 2018 11:58 AM

To: NINDS Press Team < NINDSPressTeam@ninds.nih.gov >; Burklow, John (NIH/OD) [E]

<burklowj@od.nih.gov>

Subject: FW: off-the-record question

Please advise how to respond.

I will be talking with John at 1:30 anyway.

Mark

From: Dan Hurley < hurleydan1@gmail.com > Sent: Tuesday, September 11, 2018 11:50 AM

To: Hallett, Mark (NIH/NINDS) [E] < hallettm@ninds.nih.gov>

Subject: off-the-record question

Hi Dr. Hallett: I have been speaking to many of your admirers in functional neurologic disorders, including Alberto Espay, Kathrin LaFaver, Vesper Ramos and of course Jon Stone.

Yesterday, I was told by an NIH official that you are among a group of NIH physician-scientists who are evaluating the diplomatic personnel who have developed neurologic symptoms while serving in Cuba or China. Strictly off the record, can you confirm or deny that? I was surprised only because the State Department has been adamant in sticking to the claim that an "attack" occurred, and your views expressed in the Guardian, like the views expressed to me by the other experts in functional disorders, call into question the notion of such an "attack." It's also been striking to me that the diplomats have all been sent by the State Department to UPenn, where Dr. Smith and colleagues have doubled down on their view that "brain damage" occurred as a result of an organic, external force. Some have expressed the view that this insistence on there being a mysterious, unknown, intentionally harmful cause of the diplomats' symptoms may actually be exacerbating those symptoms.

As you know, much of news reporting relies on off-the-record information from sources who ask not to be identified in print, and I can guarantee you confidentiality regarding anything you can share. I am doing a very deep dive into the science of functional disorders. It would be vitally important to know if in

fact the possibility of a functional disorder at the root of these syl panel of NIH physician-scientists. Thank you, Dan Hurley	mptoms is being explored by an expert

From: Hallett, Mark (NIH/NINDS) [E]
Sent: 11 Sep 2018 15:58:16 +0000

To: NINDS Press Team; Burklow, John (NIH/OD) [E]

**Subject:** FW: off-the-record question

Please advise how to respond.

I will be talking with John at 1:30 anyway.

Mark

From: Dan Hurley <hurleydan1@gmail.com>
Sent: Tuesday, September 11, 2018 11:50 AM

To: Hallett, Mark (NIH/NINDS) [E] <hallettm@ninds.nih.gov>

Subject: off-the-record question

Hi Dr. Hallett: I have been speaking to many of your admirers in functional neurologic disorders, including Alberto Espay, Kathrin LaFaver, Vesper Ramos and of course Jon Stone.

Yesterday, I was told by an NIH official that you are among a group of NIH physician-scientists who are evaluating the diplomatic personnel who have developed neurologic symptoms while serving in Cuba or China. Strictly off the record, can you confirm or deny that? I was surprised only because the State Department has been adamant in sticking to the claim that an "attack" occurred, and your views expressed in the Guardian, like the views expressed to me by the other experts in functional disorders, call into question the notion of such an "attack." It's also been striking to me that the diplomats have all been sent by the State Department to UPenn, where Dr. Smith and colleagues have doubled down on their view that "brain damage" occurred as a result of an organic, external force. Some have expressed the view that this insistence on there being a mysterious, unknown, intentionally harmful cause of the diplomats' symptoms may actually be exacerbating those symptoms.

As you know, much of news reporting relies on off-the-record information from sources who ask not to be identified in print, and I can guarantee you confidentiality regarding anything you can share. I am doing a very deep dive into the science of functional disorders. It would be vitally important to know if in fact the possibility of a functional disorder at the root of these symptoms is being explored by an expert panel of NIH physician-scientists. Thank you, Dan Hurley

 From:
 Gallagher, Alissa (NIH/NINDS) [E]

 Sent:
 11 Sep 2018 14:51:09 +0000

To: Koroshetz, Walter (NIH/NINDS) [E]

Subject: RE: interesting article

Indeed...

From: Koroshetz, Walter (NIH/NINDS) [E]
Sent: Tuesday, September 11, 2018 10:10 AM

To: Gallagher, Alissa (NIH/NINDS) [E] <alissa.gallagher@nih.gov>

Subject: interesting article

https://www.nbcnews.com/news/latin-america/u-s-officials-suspect-russia-mystery-attacks-diplomats-cuba-china-n908141

walter

Walter J. Koroshetz, M.D.

Director, National Institute of Neurological Disorders and Stroke

 From:
 Gallagher, Alissa (NIH/NINDS) [E]

 Sent:
 11 Sep 2018 13:36:51 +0000

To: Koroshetz, Walter (NIH/NINDS) [E];Adams, Amy (NIH/NINDS) [E];Mott, Meghan

(NIH/NINDS) [E]

Subject: News

This NBC article posted this morning: <u>U.S. officials suspect Russia in mystery 'attacks' on diplomats in Cuba, China</u>. It mentions the Aug. 14 meeting that included officials from NIH.

Thanks, Alissa From: Hallett, Mark (NIH/NINDS) [E]
Sent: 10 Sep 2018 13:22:51 +0000

To: McMakin, Barbara (NIH/NINDS) [E]

Cc: Gallagher, Alissa (NIH/NINDS) [E]; Warren, Margo (NIH/NINDS) [E]

Subject: RE: TV Interview in Atlanta

The Rounds that I am giving there relate to the treatment of dystonia, mostly hand dystonia. So I could talk about that, writer's cramp and musician's cramp and various treatments, pointing out particularly botulinum toxin.....mark

Mark Hallett, M.D., D.M.(hon) Chief, Human Motor Control Section, NINDS NIH, Building 10, Room 7D37 10 Center Dr MSC 1428 Bethesda, MD 20892-1428

Tel: 301-496-9526 Fax: 301-480-2286

email: hallettm@ninds.nih.gov

http://intra.ninds.nih.gov/Lab.asp?Org ID=72

From: McMakin, Barbara (NIH/NINDS) [E] Sent: Monday, September 10, 2018 8:57 AM

To: Hallett, Mark (NIH/NINDS) [E] <hallettm@ninds.nih.gov>

Cc: Gallagher, Alissa (NIH/NINDS) [E] <alissa.gallagher@nih.gov>; Warren, Margo (NIH/NINDS) [E]

<warrenm@ninds.nih.gov>

Subject: RE: TV Interview in Atlanta

Hi Dr. Hallett,

Thank you for your email. We wanted to follow-up with you regarding this media request. Have you given any thought to the topic you would like to discuss for the PBS show? Please let us know what you are planning to talk about and we can send through a clearance request to HHS.

Best, Barbara

## Barbara I. McMakin

Science Writer
Office of Communications and Public Liaison
National Institute of Neurological Disorders & Stroke
National Institutes of Health
Building 31, Room 8A07
31 Center Drive MSC 2540
Bethesda, MD 20892-2540
Main Office Line: (301) 496-5751

Direct Line: (301) 435-7747

## Email: memakinbi@ninds.nih.gov



From: Hallett, Mark (NIH/NINDS) [E] Sent: Friday, September 07, 2018 9:03 PM

To: Blair, Douglas S. <douglas.s.blair@emory.edu>

Cc: Watson, Jaye <jaye.watson@emory.edu>; Borich, Michael R. <michael.borich@emory.edu>; NINDS

Press Team < NINDSPressTeam@ninds.nih.gov>

Subject: RE: TV Interview in Atlanta

Happy to do it if (1) it fits with my schedule (arranged by Dr. Borich) and (2) if the NINDS Press office approves as well. I have copied both.....mark hallett

From: Blair, Douglas S. < douglas.s.blair@emory.edu>

Sent: Friday, September 7, 2018 10:42 AM

To: Hallett, Mark (NIH/NINDS) [E] < hallettm@ninds.nih.gov>

Cc: Watson, Jaye < jaye.watson@emory.edu>

Subject: TV Interview in Atlanta

Importance: High

Good morning, Dr. Hallett,

My name is Douglas Blair and I am a Senior Communications Manager at the Emory Brain Health Center, which includes the Department of Rehabilitation Medicine where you will be giving a grand rounds lecture next Wednesday.

Several months ago, we were offered a show on PBS in Georgia to feature our stories at brain health, and it launches in 8 weeks. All the stories will feature the brain and mind -- and the majority of content is from Emory faculty and patients. The show features patient centered stories that highlight treatment, the latest breakthroughs, and research. The show will be hosted by Jaye Watson (cc'd), who is a career broadcast journalist with NBC, and was hired last year to tell video stories for Emory Brain Health.

We think it's a good idea to also hear from other brain experts around the country in the show. Collaboration is an important part of research, so the more voices in the show, the better. Leadership at PBS in Georgia believe the show will spread around the country. That is certainly our hope.

I'm hoping you are available for a brief interview before or after grand rounds this coming Wednesday. The topic could be your choice. Whatever you decide to speak about will be distilled to approximately 60-75 seconds (yes, short). Some of the stories in the show are ten

minutes long but those are ones that involve patients and procedures or treatments and where we follow someone over a period of time.

The audience is not your peers, but regular people, viewers at home, so whatever you would talk about would need to be a layman's version. The PBS audience is smart and educated and interested in a deeper understanding of the brain and mind.

We have shorter segments throughout the show that give viewers 'nuggets' of information — where we won't need video outside of your interview — like why we crave carbs and fats, or why car vibrations induce drowsiness, or what we are learning about concussion research/dbs/alzheimer's/als/sleep/parkinson's/mental illness/video game addiction/opioid crisis. Yes, it's a broad range of topics under the brain/mind umbrella.

So, if there is something you'd like to talk about with us for a few minutes that you think would be interesting for the show, we can have our photographer and Jaye meet and interview you before or after you speak.

I'm sorry to ask you so late. We just decided to add other brain experts this week, so I checked grand rounds and saw you were coming.

If this is something you're not interested in, no worries. Just let me know either way.

Thank you so much! Douglas

Douglas S. Blair, Senior Communications Manager
Emory Brain Health Center | Emory University School of Medicine

Office: 404.778.5343, Cell: (b)

douglas.s.blair@emory.edu

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If you have received this message in error, please contact the sender by reply e-mail message and destroy all copies of the original message (including attachments). From: Hallett, Mark (NIH/NINDS) [E]
Sent: 6 Sep 2018 13:06:16 +0000

To: NINDS Press Team

**Subject:** FW: microwave radiation/health

From: (b) (4)

Sent: Thursday, September 6, 2018 7:11 AM

To: Hallett, Mark (NIH/NINDS) [E] <hallettm@ninds.nih.gov>

Subject: RE: microwave radiation/health

No problem, thanks for the response. Best, (b) (4)

From: Hallett, Mark (NIH/NINDS) [E] [mailto:hallettm@ninds.nih.gov]

Sent: Wednesday, September 05, 2018 11:30 PM

To: (b) (4) Cc: (b) (4)

Subject: RE: microwave radiation/health

## [EXTERNAL EMAIL]

I apologize, but I am afraid I cannot comment on this issue.

From: (b) (4)

Sent: Wednesday, September 5, 2018 5:48 PM

To: Hallett, Mark (NIH/NINDS) [E] < hallettm@ninds.nih.gov>

(b) (4)

Subject: microwave radiation/health

## Dear Dr. Hallett:

Hi, I'm trying to follow up the Cuba diplomats story. There's been much buzz about this since the Times did a piece a few days ago saying microwave weapons might have been used. Do you have any insights on whether an external microwave source is a plausible explanation for symptoms experienced by embassy personnel? Thanks much in advance. Best,

**From:** Gallagher, Alissa (NIH/NINDS) [E] **Sent:** 15 Feb 2018 03:05:29 +0000

To: Koroshetz, Walter (NIH/NINDS) [E];Schor, Nina (NIH/NINDS) [E];Adams, Amy

(NIH/NINDS) [E];Scott, Paul (NIH/NINDS) [E];Mott, Meghan (NIH/NINDS) [E]

Subject: FW: BREAKING: Medical Findings In U.S. Government Personnel Reporting

Symptoms After Exposure To Sensory Phenomena in Havana, Cuba

FYI, tomorrow's JAMA.

## Begin forwarded message:

From: "JAMA" < updates@jamanetwork.org > Date: February 14, 2018 at 6:24:30 PM EST

To: Susan Dambrauskas < dambrauskass@nhlbi.nih.gov>

Subject: BREAKING: Medical Findings In U.S. Government Personnel Reporting Symptoms After Exposure To Sensory Phenomena in Havana,

Cuba

Reply-To: "JAMA" <reply\_eugbgq\_pyabhrl@alerts.jamanetwork.com>

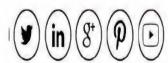
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# JAMA

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**FEBRUARY 14, 2018** 



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Randel L. Swanson II, DO, PhD; Stephen Hampton, MD; Judith Green-McKenzie, MD, MPH; et al

JAMA. Published online February 15, 2018. doi:10.1001/jama.2018.1742

Editorial: Neurological Symptoms Among US Diplomats in Cuba;

#### EDITORIAL

## Neurological Symptoms Among US Diplomats in Cuba

Christopher C. Muth, MD; Steven L. Lewis, MD JAMA. Published online February 15, 2018. doi:10.1001/jama.2018.1780

#### **MEDICAL NEWS & PERSPECTIVES**

# More Questions Raised by Concussion-like Symptoms Found in US Diplomats Who Served in Havana

Rita Rubin, MA

JAMA. Published online February 15, 2018. doi:10.1001/jama.2018.1751



uthor Interview: Clinical Findings
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ensory Phenomena in Cuba



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5

From: Koroshetz, Walter (NIH/NINDS) [E]

**Sent:** 7 Dec 2017 14:33:01 +0000

To: Hallett, Mark (NIH/NINDS) [E];McMakin, Barbara (NIH/NINDS) [E]

Cc: Warren, Margo (NIH/NINDS) [E]

Subject: RE: Media inquiry: embassy medical mystery

Yes, we should refer to outside experts. People who have studied ultrasound—Pasko Rakic at Yale studied ultrasound in development in NHP, Andrei Alexandrov chair of neurology at U of Tennessee has studied transcranial ultrasound in stroke patients, Jeff Elias at U of Virginia uses focused ultrasound for treatment of PD. Jamie Tylor studying effects of focused ultrasound on brain (https://www.nature.com/articles/d41586-017-05479-7)- Lots of experts on sound effects on the ear—hearing and balance structure—Charles Lieberman at Mass Eye and Ear Infirmary a Harvard hospital.

#### Walter

From: Hallett, Mark (NIH/NINDS) [E]

Sent: Wednesday, December 06, 2017 4:42 PM

To: McMakin, Barbara (NIH/NINDS) [E] <br/>
<a href="mailto:barbara.mcmakin@nih.gov">barbara.mcmakin@nih.gov</a>; Koroshetz, Walter (NIH/NINDS)

[E] <koroshetzw@ninds.nih.gov>

Cc: Warren, Margo (NIH/NINDS) [E] <warrenm@ninds.nih.gov>

Subject: RE: Media inquiry: embassy medical mystery

## Difficult request,

(b) (5) (b) (5)

(-/ (-/

(b) (5) will copy Dr. Koroshetz who might know who would be

appropriate.....mark

Mark Hallett, M.D., D.M.(hon)
Chief, Human Motor Control Section, NINDS
NIH, Building 10, Room 7D37
10 Center Dr MSC 1428
Bethesda, MD 20892-1428

Tel: 301-496-9526 Fax: 301-480-2286

email: hallettm@ninds.nih.gov

http://intra.ninds.nih.gov/Lab.asp?Org\_ID=72

From: McMakin, Barbara (NIH/NINDS) [E]
Sent: Wednesday, December 06, 2017 3:37 PM

To: Hallett, Mark (NIH/NINDS) [E] < hallettm@ninds.nih.gov > Cc: Warren, Margo (NIH/NINDS) [E] < warrenm@ninds.nih.gov >

Subject: Media inquiry: embassy medical mystery

Hi Dr. Hallett,

A reporter from NPR Phoenix is working on a story about the recent neurological symptoms experienced by embassy staffers in Cuba. Specifically, she would like to know how sound affects brain function and

what other causes could lead to white matter changes and cognitive dysfunction. Are there any outside experts that you could recommend for this request?

Thank you, Barbara

#### Barbara I. McMakin

Science Writer
Office of Communications and Public Liaison
National Institute of Neurological Disorders & Stroke
National Institutes of Health
Building 31, Room 8A07
31 Center Drive MSC 2540
Bethesda, MD 20892-2540

Main Office Line: (301) 496-5751 Direct Line: (301) 435-7747 Email: mcmakinbi@ninds.nih.gov



From:

Moundalexis, Athena M

Sent:

4 Apr 2018 14:21:18 +0000

To:

Tabak, Lawrence (NIH/OD) [E]

Cc:

Harrison, Brian (HHS/IOS);Gilman, James (NIH/CC/OD) [E];Gordon, Joshua

(NIH/NIMH) [E];Koroshetz, Waiter (NIH/NINDS) [E];Volkow, Nora (NIH/NIDA) [E];Johnson, Alfred (NIH/OD) [E];Simon, Dina (NIH/OD) [C];Rosenfarb, Charles H;Munoz, Mark L

Subject:

RE: Setting up a time to meet

Larry,

Thank you. We will reach out to the content experts and get back to you shortly.

Athena

Athena Moundalexis MD Regional Medical Manager Western Hemisphere Affairs 2401 E Street NW Washington, DC 20121

Office Phone 202 663 3868-

## Official - SBU UNCLASSIFIED

From: Tabak, Lawrence (NIH/OD) [E] [mailto:lawrence.tabak@nih.gov]

Sent: Wednesday, April 04, 2018 8:18 AM

To: Moundalexis, Athena M

Cc: Harrison, Brian (HHS/IOS); Gilman, James (NIH/CC/OD) [E]; Gordon, Joshua (NIH/NIMH) [E]; Koroshetz, Walter (NIH/NINDS) [E]; Volkow, Nora (NIH/NIDA) [E]; Johnson, Alfred (NIH/OD) [E];

Simon, Dina (NIH/OD) [C]

Subject: Setting up a time to meet

#### Athena.

With this note I am electronically connecting you to Drs. Gilman (<a href="https://www.cc.nih.gov/about/SeniorStaff/james\_gilman.html">https://www.cc.nih.gov/about/SeniorStaff/james\_gilman.html</a>), Gordon (<a href="https://neuroscience.nih.gov/ninds/Faculty/Profile/joshua-gordon.aspx">https://neuroscience.nih.gov/ninds/Faculty/Profile/joshua-gordon.aspx</a>), Koroshetz (<a href="https://www.ninds.nih.gov/About-NINDS/Who-We-Are/Directors-Corner">https://www.ninds.nih.gov/About-NINDS/Who-We-Are/Directors-Corner</a>), and Volkow, (<a href="https://www.drugabuse.gov/about-nida/directors-page">https://www.drugabuse.gov/about-nida/directors-page</a>) each directors of relevant NIH institutes and centers. They also strongly recommend including Dr. David Brody at USUHS, who also conducts research at NIH (<a href="https://www.usuhs.edu/national/faculty/david-brody-md-phd">https://www.usuhs.edu/national/faculty/david-brody-md-phd</a>). They are prepared to meet with you and Charles Ronsefarb as well as any other relevant content experts to be briefed on the situation discussed yesterday.

They have requested read-ahead materials detailing the medical findings so that they may best prepare.

Dina Simon in my office will coordinate with NIH staff if you could let me know dates/times when you team would be available to meet and where you want the meeting held.

Thanks, and best wishes, Larry

Lawrence A. Tabak, DDS, PhD Principal Deputy Director, NIH From:

Moundalexis, Athena M

Sent:

4 Apr 2018 16:31:07 +0000

To:

Tabak, Lawrence (NIH/OD) [E]

Cc:

Harrison, Brian (HHS/IOS); Gilman, James (NIH/CC/OD) [E]; Gordon, Joshua (NIH/NIMH) [E];Koroshetz, Walter (NIH/NINDS) [E];Volkow, Nora (NIH/NIDA) [E];Johnson, Alfred (NIH/OD) [E];Simon, Dina (NIH/OD) [C];david:brody@usuhs.edu;Munoz, Mark L;Rosenfarb, Charles H

RE: Setting up a time to meet

Attachments:

(b) (4) Proposal. doc, JPC180001 supp1 prod.pdf,

(b) (4)2018 pc 180001.pdf

While we are still working on the timing, attached please find some read-ahead materials.

For location, would you like us to come to NIH?

Dr. Brody,

We would welcome your participation.

Thanks.

Athena

#### Official

#### UNCLASSIFIED

From: Tabak, Lawrence (NIH/OD) [E] [mailto:lawrence.tabak@nih.gov]

Sent: Wednesday, April 04, 2018 8:18 AM

To: Moundalexis, Athena M

Cc: Harrison, Brian (HHS/IOS); Gilman, James (NIH/CC/OD) [E]; Gordon, Joshua (NIH/NIMH) [E]; Koroshetz, Walter (NIH/NINDS) [E]; Volkow, Nora (NIH/NIDA) [E]; Johnson, Alfred (NIH/OD) [E];

Simon, Dina (NIH/OD) [C]

Subject: Setting up a time to meet

Athena.

With this note I am electronically connecting you to Drs. Gilman

(https://www.cc.nih.gov/about/SeniorStaff/james\_gilman.html), Gordon

(https://neuroscience.nih.gov/ninds/Faculty/Profile/joshuä-gordon.aspx ), Koroshetz

(https://www.ninds.nih.gov/About-NINDS/Who-We-Are/Directors-Corner), and Volkow,

(https://www.drugabuse.gov/about-nida/directors-page) each directors of relevant NIH institutes and centers. They also strongly recommend including Dr. David Brody at USUHS, who also conducts research at NIH (https://www.usuhs.edu/national/faculty/david-brody-md-phd). They are prepared to meet with you and Charles Ronsefarb as well as any other relevant content experts to be briefed on the situation discussed yesterday.

They have requested read-ahead materials detailing the medical findings so that they may best prepare.

Dina Simon in my office will coordinate with NIH staff if you could let me know dates/times when you team would be available to meet and where you want the meeting held.

C06661409

Thanks, and best wishes, Larry

Lawrence A. Tabak, DDS, PhD Principal Deputy Director, NIH

(b) (4)

(b) (4)

## **Supplementary Online Content**

Swanson RL, Hampton S, Green-McKenzie J, et al. Neurological manifestations among US government personnel reporting directional audible and sensory phenomena in Havana, Cuba. *JAMA*. doi:10.1001/jama.2018.1742

eTable 1. Acute and Subacute Symptom Descriptions

eTable 2. Neuropsychological Test Results: Cognitive Domains

eTable 3. Neuropsychological Test Results: Effort Testing

eTable 4. Neuropsychological Test Results: Mood Functioning

eTable 5. Standardized Measures Obtained During Initial Vestibular Physical Therapy Evaluation

eTable 6. Caloric Testing Results

eTable 7. Vestibular Impairments Identified Requiring Rehabilitation Interventions

eTable 8. Standardized Measures Obtained During Initial Neuro-Optometry Evaluation

eTable 9. Clinically Significant Oculomotor Impairments Identified Requiring Dedicated Neuro-optometric Rehabilitation

eTable 10. Pure Tone Audiometry Results

eTable 11. Sleep and Headache Medication Requirements

eAppendix. Glossary of Terms

**eReferences** 

This supplementary material has been provided by the authors to give readers additional information about their work.

eTable 1. Acute and Subacute Symptom Descriptions

Domain	Acute	en. S	.(%)	Subacute	'n	(%)
	Combined	16:	(76)	Combined	19	(90)
73	Desire to change location	10	(48)	Cognitive change	.13	(62)
vio	Confusion/Disorientation	8	(38)	Memory trouble	11	(52)
- E	Agitation/Irritability	6	(29)	Difficulty concentrating	11	(52)
B	Desire to cover head/ears	5	(24)	Word finding difficulty	11	(52)
Ne Ne	Fatigue	3	(14)	Fatigue	10	(48)
nici in	Feeling of paralysis	3	(14)	Agitation/Irritability	8	(38)
90				Increased time for cognitive tasks	7	(33)
.0				Errors at work	6	(29)
	Combined	10	(48)	Combined	14	(67)
a i	Nausea	7	(33)	Dizziness	13	(62)
ibu	Dizziness	5	(24)	Falls	4	(19)
Bala				Nausea	3	(14)
	Combined	2	(10)	Combined	14	(67)
-	Visual-changes .	1	(5)	Visual changes	10	(48)
Sua	Eye pain	1	(5)	Light sensitivity	9	(43)
>				Eye strain	7	(33)
Cognitive / Bo				Difficulty focusing vision	6	(29)
	Combined	10	(48)	Combined	15	(71)
2	Ear pain	7	(33)	Tinnitus	12	(57)
jit	Tinnitus	6	(29)	Hearing change	7	(33)
Aŭ.	Hearing change	1	(5)	Noise sensitivity	5	(24)
		,		Ear pain ·	5	(24)
Sleep	Sleep problem	4	(19)	Sleep problem	16	(76)
a	Combined	11	(50)	Combined	17	(81)
5	Headache	8	(38)	Headache	17	(81)
ada	Head Pressure	5	(24)	Unilateral jaw pain	2	(10)
He	Unilateral jaw pain	.1	(5)			
Overall.	Combined acute	21	(100)	Combined subacute	21	- (100

Acute – during or hours following exposure, Subacute – days to weeks following exposure
Developed from patient descriptions of symptoms in acute and subacute period following exposure during evaluations at the
University of Pennsylvania. Clinical interviews were open-ended, therefore lack of a particular symptom was not systematically
verified

eTable 2. Neuropsychological Test Results: Cognitive Domains (n=6)

		Case				-
	- 4	9	` i1	13	15	:20
Auditory Attention and Working Memory						
Digit Span Forward	50	84	9	91	50	98
Digit Span Backward	63	63	50	95	16	95
Digit Span Sequencing	37	37	50	95	37	7
Arithmetic	91	50	37	98	25.	75
Letter-Number Sequencing	63	-50	63	99	37	50
Visual Working Memory						
Symbol Span	63	50	84	75	63	95
Auditory and Visual Memory						
Logical Memory I	84	9	75	91	50	50
Logical Memory II	63	16	37	95	50	50
Verbal Paired Associates I	95	37	91	98	63	6:
Verbal Paired Associates II	91	37.	91	95	50	50
Designs I	91	9	.50	84	91	8
Designs II	91	25	63	91	75	7
Visual Reproduction I	75	50	25	98	16	6
Visual Reproduction II	91	36	75	95	25	.50
Rey-Osterrieth Complex Figure: 3-minute delay	95	15	<10	65	40	<1
California Verbal Learning Test – II: Trials 1 – 5	84	88	84	97	95	9:
California Verbal Learning Test - II: Long Delay	63	84	50	94	25	~
Visual-Spatial Perception and Visual-Motor Construction						
Judgment of Line Orientation	>86	72	56	>86	40	
Rey-Osterrieth Complex Figure - copy	100	₹10	<10		90	60
Block Design	91	63	16	91	75	7
Motor Functions				7.		
Grooved Pegboard: Dominant	44	1.16	<1.	88	19	:<:
Grooved Pegboard: Non-Dominant	30	ر 16	2	88	9	5
Language Functioning	1 00		-	, 00		130
Boston Diagnostic Aphasia Examination: Boston Naming Test	88	50	19	7 -	25	6
Boston Diagnostic Aphasia Examination: Complex Ideational Material	58	.50	19	50	50	50
Vocabulary	63	63	75	84	63	7
Executive Functions		- 00		- 04	03	
Controlled Oral Word Association: FAS	96	39~	188	9~~	58	98
Animal Naming	58	55	-	.4	60	60
Trail Making Test: Part A	1 21	.65	88	82	97	× .
Trail Making Test: Part B	1 25	34	19	30	65	<
Ruff Figural Fluency Test: Total Designs	61	32	129	81	ŽÍ	- 5
Ruff Figural Fluency Test: Perseverative Errors	63	64	19	52	63	63
Processing Speed						
Coding	63	37	-37	91	84	10
Symbol Search	63	25	63	37.~	184	10
Academic Achievement	0,0		03		.07	- 4
Wide Range Achievement Test-4, Word Reading	47	50	61	68	63	61
Reasoning	47				03	0.1
Similarities	63	63	37	95	50	84
Matrix Reasoning	84	75	50	_ 75 <sup>-</sup>	75	
Visual Puzzles	95	84	5	-/5 98	63	63 75
Descentile scores shown Bold highlighting deadles about 150 and 150 and 151	33	04	3	38	0.5	1

Percentile scores shown. Bald highlighting denotes abnormality or <40<sup>th</sup> percentile<sup>1-1</sup>

Table 3. Neuropsychological Test Results: Effort Testing (n=6)

		A. C. C.			Ca	ise	34.	. 1 2
	7. F	1 11 11 11 1 1	4.	9.	/11	13	15	20
Effort								
Test of Men	nory Mali	ngering						
Trial 1			50	50	50	50	42	41
Trial 2			50	50	50	50	50	50
Rey 15-Item	Visual M	emory Test	15	15	15	15	12	15
- For the Te	est of Memo	alues, not percentiles ary Malingering, <sup>4-6</sup> norm al Memory Test, <sup>7-13</sup> a sco						

Table 4. Neuropsychological Test Results: Mood Functioning (n=6)

			Case	*	4	
	4	.`9!	11	13	. '15'	20
Mood Functioning 12-17						
Beck Depression Inventory-II	3	17	. 24	12	11	16
	(Min)	(Mild)	(Mod)	(Min)	(Min)	(Mild)
Beck Anxiety Inventory-Revised	2	2	14	10	5	10
	(Min)	(Min)	(Mild)	(Mild)	(Min)	(Mild)
Brief Mood Survey						
Depression	0	2	7	3	3-	3
		(Bord)	(Mod)	(Mild)	(Mild)	(Mild)
Suicidal Urges	0	0	0	0	0	0
Anxiety	1	3	11	3	4	5
	(Bord)	(Mild)	(Severe)	(Mild)	(Mild)	(Mild)
Panic	ND	0	2	1	ND	0
			(Bord)	(Bord)		
Anger	1	1" (11"	13	4	4	4
	(Bord)	(Severe)	(Severe)	(Mild)	(Mild)	(Mild)
Post-Traumatic Stress Disorder Checklist - 5	1	36 -	49	23	16	23
(Cutoff score 33)		-				
Frontal Systems Behavior Scale						
(Before/After Injury)						
Apathy	41/46	43/77	53/92	47/69	42/68	48/66
Disinhibition	36/44	57/67	49/55	50/66	39/43	37/45
Executive Dysfunction	41/45	39/67	manufacture of the second	44/56	46/68	47/75
Total	37/44	44/74	47/74	46/64	41/62	43/65
Values listed are all raw values, not percentiles					-	

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eTable 5. Standardized Measures Obtained During Initial Vestibular Physical

Therapy Evaluation

	Self-Repo	rted Measures	Obj	ective Measu	ires
Case	DHI	ABC	FGA	BESS	SOT
1	38		29	39	41
2	18	90	29	7	78
4.	38	84	28	24	71
5	38 ;	84	23	30	59
6	38 50	64	20	42	78
8	10	88	29	30	45
9	24	.76	27	41	43.
10	56	76	. 24	34	-73
11	60	76	28	23	52
12	***	***	:30	·16	52 68
13	26	86	21	30.	48
15	20		29	1,6	61
16	24	93	25	50	UTC
17	58	61	18	UTC	UTC
18	30	88	30	14	45
20	60	79	29	41	20
21	18	86	26	. 29	56

Normative values

- DHI<sup>18</sup>: Mild (0-30), Moderate (31-60), Severe (61-100) vestibular dysfunction
- -A8C<sup>19</sup>: Score < 67% indicates a risk of falling
- FGA 20: Normal is 30/30
- BESS<sup>21</sup>: Normative values used based on Iverson et al 2013<sup>22</sup>, yielding a categories (superior, above average, broadly normal, be ow average, poor, and very poor) based on age and sex. Scored 0-60, with higher scores indicating increased static balance impairment.
- -SOT<sup>23</sup>: Cut off was 70 for equilibrium score for all patients in the age group
- Bold highlighting denotes abnormality
- -Abbreviations: Dizziness Handicap Index (DHB); Activities.Balance Confidence Scale (ABC); Functional Gait Assessment (FGA); Balance Error Scoring System (BESS); Neurocom Balance Manager Sensory Organization test (SOT), Ur able to complete (UTC)

eTable 6. Caloric Testing Results

	Co	ol	Wa	rm	RV	'R*
Case	Right.	Left	Right	Left	%	R/L
1	35	3:3				
1 5	-23	201				
8	34	22	27	24	7	L
9	20	20				
10	9	3.	12	4	50	. L
11	24	13	19	7	37	L
13	12	22	22	28		
15	28	17	38	20	28	L
16	39	48	51	62	10	R
17	18	22				
18	19	20				
20.	37	8	63	12	67.	L
21	42	35				

Normal Values: RVR-threshold is <25% asymmetry. Above 25% asymmetry is diagnostic for a unilateral peripheral vestibular lesion. 24-26

- Bold highlighting denotes abnormality
- Abbreviation: Relative Vestibular Reduction (RVR)
- Evaluation of warm caloric and RVR only indicated when asymmetry observed with cool caloric per standard audiology practice.

eTable 7. Vestibular Impairments Identified Requiring Rehabilitation Interventions

Case	Static Balance	Dynamic Balance	VOR⁺ Impairment	Unilateral Peripheral Vestibular Impairment
1	X.	Х	X	
		X	X	NT
2	X	×		NT
5	. X	X	×	
5	X	X	X	· NT
8	X	X	X	
9	X	X X	X	
10	X.	X	X	X
11	X	X	X	X
12	X			NT
13	X	X	×	
15	X-	X	X	X
16	X· X·	X	X	
17	X	-X	- X	
18	Χ,	X	X	
20	X	.X	X	X
21	X	X	X	
n	16	16	15	4
(%)	(76)	(76)	(71)	(31)*

<sup>+</sup> Vestibulo-ocular reflex (VOR)

Abbreviations: Not tested (NT)

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<sup>\*</sup>Percentage is based on 13 individuals who underwent caloric evaluation

eTable 8. Standardized Measures Obtained During Initial Neuro-Optometry Evaluation

	Self-Reported Measure		Objective	Measures					
		NPC (cm)							
Case	CISS*	Break	Recovery	PFV (PD)	DEM (sec)				
1	40	7.5	<b>13</b> · 5	35	29				
2	-	2.5	5	25	25				
4		2.5	5	25	32				
5	76	13	20	12	40				
6		10	15	30	27				
9	40	12	23	20	-53				
10		4	7.5	40	27				
11	74	7.5	13	16	58				
13	51	10	15	18	40				
14		5	7.5	30	50				
15	46	13	25	6	40				
16	77	7.5	15	30	74				
17	67	25	40	18	67				
18		5	8	18	38				
20	57	7.5	30	6	90				

## Normative values

- Abnormal CISS<sup>27</sup> is >= 16 Abnormal NPC<sup>28,29</sup> is >= 6cm break and >=8cm forRecovery Abnormal PFV<sup>28,29</sup> <=20 prism diapters (PD) base out.
- Abnormal DEM 28,30 is >= 30 seconds
- Bold highlighting denotes abnormality
- -Abbreviations: Convergence Insufficiency Symptom Survey (CISS); Near Point of Convergence (NPC); Positive Fusional Vergence (PFV); Prism Diopters (PD); Developmental Eye Movement Test (DEM)
- \* CISS obtained at initiation of neuro-optometric rehabilitation when indicated per standard neuro-optometry practice.

eTable 9. Clinically Significant Oculomotor Impairments Identified Requiring

Dedicated Neuro-optometric Rehabilitation (n=11)

Case	Convergence Insufficiency	Accommodative Insufficiency	Saccadic Dysfunction	Pursuit Dysfunction	Photophobia
1	Χ .	*		X	X.
5	x	.*	X	· X	X.
6	X			X	X.
9	х .	*	X		
11	×	X	X	X	χ,
13	X	*	X	X	X.
15	X	*	X	X	X
16	X .	X	X	X	X
17	X	*	X	. X	X.
18	X		X	X	
20	X	*	X	X	X.
n	11	÷2	9	. 10	9
(%)	(100)	(18)	(82)	(91)	(82)

<sup>\*</sup>Measurements consistent with accommodative insufficiency and historical description of visual change after exposure, however formal diagnosis limited over the age of 40 due to age-appropriate presbyopia. -clinical diagnosis of convergence insufficiency, accommodative insufficiency, saccadic and pursuit dysfunction, and photophobia was performed according to the standards detailed in the methods section, and included integration of standardized measures along with expert clinical evaluation.

of the 4 individuals listed in Table 1 above that did not require formal New-o-optometric rehabilitation at Penn, one received neuro-optometric rehabilitation after exposure but prior to Penn evaluation, two had oculomotor exercises integrated into vestibular and/or occupational therapy, and was provided a home exercise program.

eTable 10. Pure Tone Audiometry Results

						Frequency	(Hz)				
Case	9	250	500	1000	1500	2000	3000	4000	6000	8000	
1	R	10	15	10		15	10	10	15	15	
	L	10	10	10		5	10	10	15	15	
5*	R	15	15	20		20	25	15	5	10	
	L	15	15	20		20	20	15	5	5	
8	R	10	5	5		10	10	5	10	10	
	L	15	10	5		10	15	15	10	5	
9†	R	10	5	5		10	40	45.	30.	20	
	L	15	5	10		10	.55	35	20	10	
10‡	R	5	10	5		15	30	15	5	20	
	L	30	35	40	50	55	55	60	75	95	
11‡	R	15	15	15		10	15	10	15	5	
	L	50	40	,35		30	30	25	25	10	
135	R	15	15	10		10	15	10	1 25	20	
	L	20	20	15		15	20	25	35	30	
15	R	5	5	15		10	15	20	20	15	
	L	5	15	10		20	15	20	20	20	
16	R	20	20	15		20	15	15	15	20	
	L	10	15	15		15	15	15	15	15	
17§	R	15	20	15		20	25	25	20	15	1
	L	20	20	20		10	15	25	20	15	
18	R	5	10	10		5	10	5	10	10	
	L	10	10	5		1Ò	15	10	15	15	
20‡	R	50	45	45	40	25	25	25.	. 25	20	
	L	45	45	40	· 35	25	25	20	25	20	
21	R	10	15	5		10	5	5	10	10	
	L	15	15	15		10	10	5	10	10	

-Results from Pure Tone Audiometry performed as part of a comprehensive audiological assessment which included Speech Audiometry

- normal is <= 20 dB at each frequency.
- Bold highlighting denotes abnormality
- \* Case 5: isolated impairment with unclear clinical relevance.
- † Case 9: mild to moderate SNHL, no hearing aid indicated.
- ‡ Cases 10, 11, and 20: moderate to sever SNHL, received hearing aid.
- § Cases 13 and 17: borderline to mild SNHL, no fiearing aid indicated.

<sup>-</sup> NOTE: of the 4 cases with sensorineural hearing loss (SNHL) above (9,10, 11, 20), none of the individuals report noticing or being diagnosed with hearing loss prior to exposure. One individual did réport frequent ear infections as a child, though reported normal functional hearing until exposure.

eTable 11. Sleep and Headache Medication Requirements

Case	Impair Subjective Complaint	ed Sleep Medication Required	Hea Subjective Complaint	dache Medication Required	Specific Medications Used Included:			
1	'X·	X						
2	X	1	X		Headache Medications	N		
3					Acetaminophen/Aspirin/Caffeine	8		
4					Rizatriptan	5		
5	X	×	X	X	Sumatriptan	1		
6			X	X	Butalbital/Acetaminophen/Caffeine	1		
7	X	X			Gabapentin	4		
8	Ϋ́Х	X	X		Propranolol	2		
9	X	X	X	:X	Topiramate	1		
10	· 'X		X	X	Amitriptyline	1		
11	X	X	x'	×	Riboflavin	2		
12	X	i	. X	.X				
13	X.	X	.X	X	Sleep Medications	N		
1.4	Х	X	X		Melatonin	10		
15	X	X	X.	X	Doxepin	6		
16	Х	X	X.	X	Gabapentin	6		
17	-X.	X	X	-X-	Trazodone	3		
18	X	X	X	X				
19								
20	X	×	Χ.	-X-	Medications were selected based on clinical			
21	.X	×	X.		indication, efficacy, and tolerance, and were			
n	18	-15	16	12	adjusted as clinically indicated. Efforts were made	de		
(%)	(86)	(71)	(76)	(57.)	to minimize cognitive side effects			

eAppendix. Glossary of Terms

Activities Balance Confidence Scale<sup>19,31</sup> (ABC): is a widely used self-reported standardized measure which asks a patient to rate their perceived confidence in performing various mobility / movement tasks without a loss of balance or fall. A score of < 67% on this measure indicates that the patient is at risk of falling.

Balance Error Scoring System<sup>21,22</sup> (BESS): a standardized test of static balance, which evaluates the ability to maintain stability while performing double limb stance, non-dominant single limb stance, and tandem stance, each on both a firm surface and on foam. Scoring ranges from 0-60, with normative categories (superior, above average, broadly normal, below average, poor, and very poor) based on age and sex.

Caloric Reflex Testing<sup>24-26</sup>: Standardized test to evaluate peripheral vestibular end organs, and the clinical gold-standard test identifying a unilateral peripheral vestibulopathy. Interpretation of caloric testing is done by looking at the Relative Vestibular Reduction (RVR) percentage, with an RVR of > 25% asymmetry being diagnostic for a unilateral peripheral vestibular lesion.

Clinical Test of Sensory Organization and Balance<sup>32,33</sup> (CTSIB): a non-instrumented, quantitative method of evaluating postural control in different sensory conditions.

Computerized Dynamic Posturography<sup>23</sup> (CDP): an instrumented method of quantitating balance functioning. This case series utilized the Sensory Organization Test, a form of CDP, which quantitates the use of visual, proprioceptive, and vestibular cues to maintain postural stability. Given the age group of this case series, a cut off value of 70 for equilibrium score was used to define pathology.

Convergence Insufficiency Symptom Survey<sup>27</sup> (CISS): a self-reported measure used to quantify symptoms related to convergence insufficiency and oculomotor dysfunction, and to track symptom

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improvement throughout neuro-optometric rehabilitation. Abnormal CISS is >= 16, and indications ongoing symptoms related to convergence insufficiency and/or oculomotor dysfunction.

Developmental Eye Movement Test<sup>28,30</sup> (DEM): a timed visual-verbal test used to evaluate saccadic eye movement speed and accuracy. Abnormal DEM performance time is >= 30 seconds, and indicates dysfunction of saccadic eye movements.

**Directional Phenomena**: a term used throughout the manuscript to describe the perception of sound, pressure, and/or vibration emanating from a distinct direction in space.

Dizziness Handicap Index<sup>18</sup> (DHI): a standardized measure of perceived impairment related to dizziness, which correlates with vestibular dysfunction: Scoring ranges between mild (0-30), Moderate (31-60), and Severe (61-100) impairment.

Dynamic Balance: the ability to maintain postural orientation and postural stability while the body is in motion (ex. walking, running). This is often measured using the Functional Gait Assessment (see below).

Functional Gait Assessment<sup>20</sup>(FGA): is a standardized measure used to identify abnormalities in dynamic balance. There are 10 gait conditions (gait with: level surfaces, change gait speed, horizontal head movements, vertical head movements, pivot turns, stepping over an obstacle, narrow base of support (tandem gait), eyes closed, and ambulating backwards) which are each scored from 0 to 3 (0= severé impairment, 1= moderate impairment, 2= mild impairment, 3=normal). Normative score of 30/30.

Near Point of Convergence 28,29 (NPC): the closest distance (in cm) at which the patient is no longerable to maintain single vision. It is measured from the brow above the nose and represents the maximum

total convergence response. Target is a small letter on a tongue depressor or a penlight. Normative cutoff is 6 cm.

Neuropsychological Testing / Battery: 1-17. A comprehensive assessment of cognitive, neurobehavioral and mood functioning that is performed by a highly trained neuropsychologist. Neuropsychological evaluations typically last for multiple hours, consisting of a thorough clinical interview (e.g., basic demographic information including family, educational and employment history, as well as environmental event details), self-reported symptoms, mood inventories, and extensive objective testing of cognitive domains (e.g., executive functioning, memory, attention, working memory, visual-spatial perception, visual-motor construction, motor functioning, language, reasoning, processing speed, academic functioning).

Positive Fusional Vergence <sup>28,29</sup> (PFV) [also known as fusional convergence]: the maximum amount of disparity vergence measured with prisms before a patient reports blur or diplopia. Test distance is 40 cm and normative cut-off is 20 prism diopters base out.

Static Balance: the ability to maintain both postural orientation and postural stability while standing still. Static balance is assessed in under multiple conditions, including firm surfaces, unstable surfaces (Ex. foam), both with eyes open and eyes closed.

Vestibulo-ocular reflex<sup>25</sup> (VOR): a complex neurologic reflex that coordinates eye and head movements to maintain focus on a visual target.

Vestibular / Ocular-Motor Screening<sup>34</sup> (VOMS): standardized measure to quantify symptomatic responses to clinical vestibular and oculomotor testing, specifically evaluation of saccadic eye movements, smooth pursuits, vergence, VOR, and visual motion sensitivity.

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Research

JAMA | Preliminary Communication

## Neurological Manifestations Among US Government Personnel Reporting Directional Audible and Sensory Phenomena in Havana, Cuba

Randel L. Swanson II, DO, PhD; Stephen Hampton, MD; Judith Green-McKenzie, MD, MPH; Ramon Diaz-Arrastra, MD, PhD; M. Sean Grady, MD; Ragini Verma, PhD, Rosette Biester, PhD; Diana Duda, PT, DPT; Ronald L. Wolf, MD, PhD; Douglas H. Sinith, MD

IMPORTANCE From late 2016 through August 2017, US government personnel serving on diplomatic assignment in Havana, Cuba, reported neurological symptoms associated with exposure to auditory and sensory phenomena.

OBJECTIVE To describe the neurological manifestations that followed exposure to an unknown energy source associated with auditory and sensory phenomena.

DESIGN. SETTING. AND PARTICIPANTS Preliminary results from a retrospective case series of US government personnel in Havana. Cuba. Following reported exposure to auditory and sensory phenomena in their homes or hotel rooms, the individuals reported a similar constellation of neurological symptoms resembling brain injury. These individuals were referred to an academic brain injury center for multidisciplinary evaluation and treatment.

**EXPOSURES** Report of experiencing audible and sensory phenomena emanating from a distinct direction (directional phenomena) associated with an undetermined source, while serving on US government assignments in Havana, Cuba, since 2016.

MAIN OUTCOMES AND MEASURES Descriptions of the exposures and symptoms were obtained from medical record review of multidisciplinary clinical interviews and examinations. Additional objective assessments included clinical tests of vestibular (dynamic and static balance, vestibular occular reflex, testing, caloric testing), oculomotor (measurement of convergence, saccadic, and smooth pursuit eye movements), cognitive (comprehensive neuropsychological battery), and audiometric (pure tone and speech audiometry) functioning. Neuroimaging was also obtained.

RESULTS Of 24 individuals with suspected exposure identified by the US Department of State, 21 completed multidisciplinary evaluation an average of 203 days after exposure. Persistent symptoms (>3 months after exposure) were reported by these individuals including cognitive (n = 17, 81%), balance (n = 15, 71%), visual (n = 18, 86%), and auditory (n = 15, 68%) dysfunction, sleep impairment (n = 18, 86%), and headaches (n = 16, 76%). Objective findings included cognitive (n = 16, 76%), vestibular (n = 17, 81%), and oculomotor (n = 15, 71%) abnormalities. Moderate to severe sensorineural hearing loss was identified in 3 individuals. Pharmacologic intervention was required for persistent sleep dysfunction (n = 15, 71%) and headache (n = 12, 57%). Fourteen individuals (67%) were held from work at the time of multidisciplinary evaluation. Of those, 7 began graduated return to work with restrictions in place, home exercise programs; and higher-level work-focused cognitive rehabilitation.

CONCLUSIONS AND RELEVANCE In this preliminary report of a retrospective case series, persistent cognitive, vestibular, and oculomotor dysfunction, as well as sleep impairment and headaches, were observed among US government personnel in Havana, Cuba, associated with reports of directional audible and/or sensory phenomena of unclear origin. These individuals appeared to have sustained injury to widespread brain networks without an associated history of head trauma.

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Author Affiliations: Author affiliations are listed at the end of this

Corresponding Author: Douglas H. Smith, MD, Department of Neurosurgery and Center for Brain Injury and Repair. University of Pennsylvania. Perelman School of Medicine, 3320 Smith Walk, 105 Hayden Hali, Philadelphia, PA 19104 (smithdou@upenn.edu).

Research Preliminary Communication

n late 2016, US government personnel serving in Havana, Cuba, began presenting to their embassy medical unit after experiencing unusual auditory and/or sensory stimuli of variable intensity and character, with associated onset of varied neurological manifestations. Initial signs and symptoms pointed toward injury of the auditory system, leading to the establishment of a triage program at the University of Miami centered around otolaryngology evaluation. Eighty embassy community members underwent initial evaluation between February and April 2017, and 16 individuals were identified with similar exposure history and a constellation of neurological signs and symptoms commonly seen following mild traumatic brain injury, also referred to as concussion. Exposures continued with time and 8 additional individuals were identified who had similar findings. The US Department of State, Bureau of Medical Services, subsequently convened an expert panel in July 2017, which came to consensus that the triage findings were most likely related to neurotrauma from a nonnatural source andrecommended that further investigation into this novel cluster of findings was necessary.

The University of Pennsylvania's Center for Brain Injury and Repair was subsequently selected to coordinate multidisciplinary clinical evaluation, treatment, and rehabilitation of individuals identified during initial triage and additional patients with exposure. The purpose of this preliminary communication is to describe preliminary findings from 21 patients who were exposed to the same nonnatural source.

## Methods

#### Design

This retrospective study was approved by the institutional review board of the University of Pennsylvania's Perelman School of Medicine, which waived the need for informed consent. The participants signed general consent forms for treatment permitting use of their data in research. Because of security and confidentiality considerations, individual-level demographic data cannot be reported.

#### Clinical Approach

The US Department of State directly referred individuals with suspected exposure to the University of Pennsylvania for comprehensive evaluation and treatment. A multidisciplinary team was convened consisting of physical medicine and rehabilitation, occupational medicine, neurology, neuroradiology, and neurosurgery. Each specialist independently obtained clinical histories and conducted comprehensive assessments. Reported signs and symptoms were extracted from these interviews.

Based on individual clinical indication, additional referrals were made to vestibular physical therapy, neuro-optometry, neuropsychology, occupational therapy, speech therapy, audiology, otorhinolaryngology, and sleep medicine for focused evaluation and treatment. Patients were referred to the University of Pennsylvania for clinical care, as opposed to enrollment in a structured research study. The Box shows

#### **Key Points**

Question Are there neurological manifestations associated with reports of audible and sensory phenomena among US government personnel in Havana, Cuba?

Findings In this case series of 21 individuals exposed to directional audible and sensory phenomena, a constellation of acute and persistent signs and symptoms were identified, in the absence of an associated history of blunt head trauma. Following exposure, patients experienced cognitive, vestibular, and oculomotor dysfunction, along with auditory symptoms, sleep abnormalities, and headache.

Meaning The unique circumstances of these patients and the consistency of the clinical manifestations raised concern for a novel mechanism of a possible acquired brain injury from a directional exposure of undetermined etiology

an abbreviated list of objective measures used during clinical assessments and supplements for additional information.  $^{2-29}$ 

#### Cognitive, Neurobehavioral, and Mood Evaluations

When clinically indicated, comprehensive neuropsychological assessments were conducted by experienced neuropsychologists, who were not blinded to patient status. Neuropsychological test batteries included assessment of the following domains: (1) auditory attention; (2) auditory and visual working memory, (3) auditory and visual memory, (4) visual-spatial perception, (5) visual-motor construction, (6) motor function, (7) language function, (8) executive function, (9) processing speed, (10) academic achievement, (11) reasoning, (12) mood functioning, and (13) effort (Box and eAppendix in the Supplement). Following neuropsychological testing, individuals with cognitive deficits were referred for cognitive rehabilitation with occupational therapy, speech therapy, or both, depending on the individual clinical indication. Cognitive rehabilitation was intentionally not started prior to completion of neuropsychological testing to avoid affecting results.

#### Balance and Vestibular Evaluations

Clinical evaluations identifying balance abnormalities prompted referral to vestibular physical therapy. Focused vestibular evaluation included expert clinical assessment and the use of validated measures of static and dynamic balance (Box). <sup>15-21</sup> Also per clinical indications, patients were referred to audiology for comprehensive evaluation of the peripheral vestibular system, including caloric reflex testing. <sup>23,24</sup> Individuals confirmed to have a unilateral peripheral vestibular peripheral vestibular reduction of ≥25% on caloric reflex testing) underwent magnetic resonance imaging (MRI) of the head with and without gadolinium contrast, with focus on the internal auditory canals in addition to the MRI sequences detailed.

#### **Oculomotor Evaluations**

Individuals found on clinical evaluation to have abnormalities of oculomotor function were referred to neuro-optometry for further evaluation and treatment. Oculomotor function was

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quantified using the following standard optometric clinical measures (Box). 25,26 Vergence testing included step vergence with prism bar, vergence facility with prisms, and near point of convergence: Accommodative testing in nonpresbyopic patients included amplitude of accommodation, accommodative facility with plus and minus lenses, and accommodative lag. Pursuit and saccadic testing was done qualitatively to assess accuracy of tracking eye movements and whether symptoms were provoked as with Vestibular/Ocular Motor Screening.29 Saccadic speed and accuracy were quantified using the Developmental Eye Movement test, 26.28 a timed visual-verbal test. Diagnoses of accommodative, vergence, and/or saccadic/pursuit dysfunction were made using standardized criteria, in conjunction with symptomatic reporting, 26 which were quantified using the Convergence Insufficiency Symptoms Survey.27.

#### **Auditory Evaluations**

Audiometry evaluations were performed prior to referral for care at the University of Pennsylvania. However, when patients had balance function testing as described here, comprehensive audiology evaluation included both pure tone and speech audiometry.

#### **Imaging Evaluations**

Initial conventional MRI sequences were acquired at 3T on a Siemens Magnetom Prisma<sup>fit</sup> scanner, and included high-resolution sagittal 3-dimensional MP-RAGE, T2 SPACE and FLAIR SPACE, coronal 2-dimensional T2-weighted imaging, axial 2-dimensional diffusion-weighted imaging, and axial T2\* gradient echo. Resulting images were clinically interpreted by neuroradiology clinicians.

#### Results

There were 21 individuals evaluated (11 women and 10 men, with a mean age of 43 years). Multidisciplinary evaluations began an average of 203 days (range, 3-331 days; median, 189 days; interquartile range, 125 days) following exposure (Table 1).

#### Exposure

For 18 of the 21 individuals (86%), there were reports of hearing a novel, localized sound at the onset of symptoms in their homes and hotel rooms (Table 2). Affected individuals described the sounds as directional, intensely loud, and with pure and sustained tonality. Of the patients, high-pitched sound was reported by 16 (76%), although 2 (10%) noted a low-pitched sound. Words used to describe the sound include "buzzing," "grinding metal," "piercing squeals," and "humming."

The sounds were often associated with pressurelike (n=9, 43%) or vibratory (n = 3, 14%) sensory stimuli, which were also experienced by 2 of the 3 patients who did not hear a sound. The sensory stimuli were likened to air "baffling" inside a moving car with the windows partially rolled down.

Both the sound and sensory stimuli were often described as directional in that the individuals perceived a distinct direction from which the sensation emanated (hereafter re-

Box: Examples of Standardized Measures Used in Clinical Assessments Cognitive Boston Diagnostic Aphasia Examination<sup>2</sup> California Verbal Learning Test-2nd Edition<sup>3</sup> Grooved Pegboard Test of Memory Malingering<sup>5</sup> Trail Making Test, Parts A and B<sup>6</sup> Wechsler Adult Intelligence Scale-IV7 Wechsler Memory Scale-IV® Mood Beck Depression Inventory (2nd edition)9 Beck Anxiety Inventory 10,11 Frontal Systems Behavior Scale<sup>12</sup> Post-Traumatic Stress Disorder Checklist 13,14 Balance and vestibular Functional Gait Assessment<sup>15</sup> Activities Specific Balance Confidence 16 Balance Error-Scoring System<sup>17</sup> Clinical Test of Sensory Organization and Balance 16,19 Dizziness Handicap Index20 Computerized Dynamic Posturography 21.22 Caloric reflex test<sup>23 24</sup> Jision and oculomotor Formal Evaluation of Vergence and Accommodation 25:26 Convergence Insufficiency Symptoms Survey 27 Developmental Eye Movement Test<sup>26,28</sup> Vestibular/Ocular Motor Screening 39 Measures were used based on clinical indications; therefore, every patient

 Measures were used based on clinical indications; therefore, every patient did not complete all measures in this abbreviated list.

ferred to as directional phenomena). Further, the directional phenomena appeared to be localized to a precise area, as individuals (n = 12,57%) noted that after changing location, the sensation disappeared and the associated symptoms reduced. Five individuals (24%) reported covering their head and/or ears, although doing so did not result in attenuation of the directional phenomena.

Accurately determining the dose and duration of exposure has been difficult because of the limitations of patient recall. Some patients were awakened by sounds and were unsure of the start of the event. The shortest reported event involved two 10-second pulses reported as a single exposure episode, whereas other patients reported that they perceived sound continuously for longer than 30 minutes. Owing to security concerns, further details of potential cosage cannot be provided.

Of the affected individuals, 20 (95%) reported immediate onset of neurological symptoms associated with directional phenomena (eTable 1 in the Supplement). One individual awoke from sleep with acute symptoms (including headache, unilateral earpain, and hearing changes) but did not perceive directional phenomena. From days to weeks after exposure, individuals reported that they experienced the onset

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Clinical Findings and Outcomes in US Government Personnel Reporting Directional Sensory Phenomena in Cuba

Table 1. Demographics of Patients Evaluated at the University of Pennsylvania*					
	Men (n = 10)	Women (n = 11)	Total (N = 21)		
Age, mean (SD), y	·39 (7)	47 (8)	43 (8)		
Time from exposure to evaluation mean (SD), d	229 (98)	180 (85)	203 (93)		

Potentially identifying information intentionally omitted for security and privacy concerns.

Table 2. Exposure Descriptions of the Directional Phenomena

	Associated S	Associated Sound			Associated Sensory Stimuli			Duration >3 n	Duration >3 mo		
Patient No.	Reported	High Pitch	Low Pitch	Reported	Pressure	Vibration	Movement Attenuation <sup>3</sup>	Persistent Symptoms	Objective Findings	Required Treatment	
1	Х	Х					X	Х	Х	х	
2	X	Х			100° 0 0 1900		x -	*	X	X	
3	x	x -		• (			×				
4	х —		x	х		х		ж	X	χ	
5	x	X		X	X			×	X	x	
6	X		χ	χ .	x		X	X	X	х	
7	beliefe d'expens tres equant			Х	X		X	Х			
8 -	X	X	-				,X	X	X	Χ	
9	X	X		X		Х		Х	X	Х	
10	×	x		X		X		X	Х	x.	
11	X	х		Х	Χ.			Х	X	x	
12	×	x		×	×			×	х	х	
13	X	X	-   -	•			x	×	×	×	
14	Х	X					Х	х	Х	X	
15	X	X		X	X		X	X	х	X	
16	X	x					χ	х	χ .	X	
17	x	X-		x	X		χ	X	х	. х	
18	o stor numberity o							×	X	X	
19	χ -	х	-	×	X			×			
20	•	•		x	. X.		â	X	X	X	
21	x	x						X	×	×	
No. (%)	18 (86)	16 (76)	2 (10)	12 (57)	9 (43)	3 (14)	12 (57)	20 (95)	18 (86)	18 (86)	

Patients reported attenuation of saund, pressure, or vibration when moving to a different location.

of additional cognitive; neurobehavioral/mood, and physical symptoms. Twenty individuals (95%) reported that they experienced persistent (>3 months) symptoms, and 18 individuals (86%) exhibited objective clinical manifestations in 6 predominant domains (Table 3).

#### Cognitive, Neurobehavioral, and Mood Findings

Persistent cognitive manifestations were reported by 17 individuals (81%). Subjective symptoms included memory problems (n = 16, 76%), feeling mentally foggy (n = 16, 76%), impaired concentration (n = 15, 71%), and feeling cognitively slowed (n = 14, 67%) (Table 3). In addition, they reported neurobehavioral difficulties including irritability (n = 14, 67%), nervousness (n = 12, 57%), feeling more emotional (n = 11, 52%), and sadness (n = 5, 24%). Fo: at least 6 individuals (29%), a clear change in work performance was noted by supervisors and colleagues (eTable 1 in the Supplement). Individuals also reported a "good day-bad day" pattern where significant cognitive or physical exertion would be followed by exacerbation of their symptoms for several days. Cognitive symptoms, as well as disequilibrium and headache, reportedly were also frequently exacerbated by car-liovascular exercise.

Multidisciplinary evaluations raised concern for cognitive impairment in 16 individuals (75%). Prior to referral, 4 of these individuals underwent neuropsychological evaluation (data not shown as generated outside of the University of Pennsylvania). Repetition of comprehensive neuropsychological testing is precluded within 1 year due of practice effects when material is presented within this timeframe. With previous exposure to material, the individual may score higher on a repeated neuropsychological evaluation within 1 year. Neuropsychological assessments were performed on 10 individuals after referral. Of those, interpretation was ongoing in 4 at the time of this publication. Per their preference, 2 individuals did not complete neuropsychological testing.

For the 6 individuals with complete neuropsychological testing data and analysis at the University of Pennsylvania, all had significant areas of cognitive weakness and/or impairment (eTables 2, 3, and 4 in the Supplement). Impairments were found in executive function (n = 6), motor function (n = 5), auditory and visual memory (n = 4), visual-spatial perception and visual-motor construction (n = 4), auditory attention and working memory (n = 3), language (n = 3), processing speed (n = 4), and reasoning (n = 1). All individuals

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Table 3 Prevalence of	Persistent Symptoms an	d Objective Findings*

	Subjective		Objective		
Domain	Symptom	No. (%)	Finding	No. (%)	
Cognitive and behavioral	Combined	17 (81)	Neuropsychological testing indicated	16 (76)	
	Difficulty remembering	16 (76)	Neuropsychological testing performed at Penn	10 (48)	
	Mental log	16 (76)	Neuropsychological testing outside Penn	4(19)	
	Difficulty concentrating	15 (71)	Neuropsychological testing not yet performed	2 (10)	
	Feeling slowed	14 (67)	Cognitive rehabilitation	13 (62)	
	Irritability	14 (67)	•		
	Feeling more emotional	11 (52)			
Balance and vestibular	Conibined	15 (71)	Vestibular physical therapy referral	17 (81)	
	Balance problems	14 (67)	Static postural stability	16 (76)	
	Dizziness	13 (62)	Dynamic balance	16 (76)	
	Nausea	7 (33)	VOR dysfunction	15 (71)	
			Unitateral catoric impairment	4 (31)	
			Vestibular rehabilitation	17 (81)	
Vision and oculomotor	Combined	18 (86)	Neuro-optometry referral	15 (71)	
	Visual problems	16 (76)	Convergence insufficiency	11 (52)	
	Light sensitivity	13 (62)	Smooth pursuit dysfunction	11 (52)	
	Difficulty reading	12 (57)	Saccadic dysfunction	10 (47)	
	Eye strain	11 (52)	Neuro-optometric rehabilitation	14 (67)	
Auditory	Combined	15 (68)	. Audiology referral	13 (62)	
	Sound sensitivity	14 (67)	Moderate to severe SNHL	3 (23)	
	Tinnitus.	12 (57)	Hearing aid provided	3 (14)	
	Hearing reduction	9 (43)			
	Ear pressure	8 (38)			
Sleep	Combined	18 (86)	Pharmacological intervention	15 (71)	
	Drowsiness or fatigue	16 (76)			
	Decreased sleep duration	15 (71)			
	Trouble falling asleep	14 (67)			
Headache	Combined	16 (76)	Pharmacological intervention	12 (57)	
	With cognitive tasks	13 (62)			
	With therapy	1.1 (52)			
	Due to photophobia	9 (43)			
	Due to phonophobia	6 (29)			
District	Combined subjective	.20 (95)	Combined objective	18 (86)	

Abbreviations: Penn, University of Pennsylvania, SNHL, sensorineural hearing loss: VOR, vestibulo-ocular reflex.

demonstrated a high level of effort during testing and had intact cognitive domains including visual working memory and academic achievement.

Neurobehavioral function was evaluated using the Frontal System Behavior Scale, a self-report measure of frontal lobe dysfunction. Specifically, comparing before and after exposure retrospectively via patient recall and self-report, individuals noted apathy (n = 5), executive dysfunction (n = 4% and disinhibition (n = 2). Two individuals met criteria for post-traumatic stress disorder and endorsed severe levels of anger on the Brief Mood Survey, 1 of whom also endorsed moderate to severe levels of depression and anxiety.

#### Balance and Vestibular Findings

Individuals described acute nausea (n = 7, 33%) and dizzness (n = 5, 24%) during exposure, which continued to progress

in the subacute and persistent stages (acute stage = during or hours following exposure; subacute stage = days to weeks after exposure patient recall); and persistent stage = more than 3 months after exposure). Specifically, more than 3 months after exposure, individuals reported a higher prevalence of dizziness (n = 13, 62%) and causea (n = 7, 33%), in addition to general balance problems (n = 14, 67%) (Table 3). These symptoms were exactibated by walking quickly, tasks involving head movements, complex visual environments, or in some cases while simply standing still. Balance symptoms were also worsened with eyes closed or in low light conditions.

Clinical examinations raised concert for balance impairment in 17 patients (81%), prompting referral to vestibular physical therapy. Focused vestibular evaluations demonstrated impairments in static postural stability (n = 16, 76%), dynamic

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<sup>&</sup>lt;sup>a</sup> Persistent defined as presence more than 3 months after exposure.

bNeuropsychological characterization ongoing. Start of cognitive rehabilitation held until neuropsychological testing performed.

Of 13 patients tested thus far during persistent symptom evaluation,

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balance (n = 16, 76%), and the vestibulo-ocular reflex (n = 15, 71%) (eTables 5, 6, and 7 in the Supplement). Patients with the most severe balance impairments on clinical evaluation underwent caloric reflex testing, which demonstrated peripheral vestibular dysfunction in 4 of 13 patients evaluated. MRI findings focusing on the internal auditory canals on these 4 patients were normal. Taken together, these balance symptoms and evaluation findings are consistent with central and, in some cases, peripheral vestibular abnormalities.

#### Oculomotor Findings

Of the individuals with persistent symptoms, 16 (76%) reported visual problems (Table 3). Light sensitivity (n=13,62%) and difficulty reading (n=12,57%) were also frequently reported. Eye strain (n=11,52%) was experienced particularly with reading and was associated with headaches, disequilibrium, and nausea.

Clinical examinations raised concern for oculomotor dysfunction in 15 individuals (71%), prompting referral to neuro-optometry. The most common findings confirmed on focused oculomotor evaluation were convergence insufficiency (n  $\approx$  11, 52%), abnormal smooth pursuits (n  $\approx$  11, 52%), and saccadic dysfunction (n  $\approx$  10, 47%) (eTables 8 and 9 in the Supplement). Similar to vestibular testing that provoked symptoms, oculomotor examination elicited headache and disequilibrium.

#### **Auditory Findings**

At the onset of the directional phenomena, affected individuals reported hearing a loud sound (n=18,86%), associated with ear pain (n=7,33%) and tinnitus (n=6,29%). Within days to weeks following exposure, individuals continued to report tinnitus (n=12,57%) and ear pain (n=5,24%), with the addition of a change in hearing (n=7,33%) and sensitivity to noise (n=5,24%). More than 3 months after exposure, sound sensitivity was the most common auditory concern (n=14,67%), followed by tinnitus (n=12,57%) and ear pressure (n=8,38%).

While 9 individuals (43%) reported persistent hearing reduction, pure tone audiometry, including pure tone average and word identification, revealed moderate to severe sensorineural hearing loss in 3 individuals (23%) (eTable 10 in the Supplement), who were fitted with hearing aids. For 2 individuals, the moderate to severe sensorineural hearing loss was unilateral and corresponded with the side of peripheral vestibular dysfunction on caloric testing. Otoscopy and tympanometry findings were unremarkable.

#### Sleep

Individuals commonly reported issues with sleep (n=18,86%), including reduced sleep duration (n=15,71%) and difficulty falling asleep (n=14,67%). In addition, individuals experienced significant daytime fatigue (n=16,76%). Most individuals required pharmacological intervention to improve subjective report of sleep architecture (n=15,71%) (eTable 11 in the Supplement).

#### Headaches

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At the initiation of directional phenomena exposure, 8 individuals (38%) reported immediate onset of headache, while 5

(24%) reported intense head pressure. In the days to weeks following exposure, 17 individuals (81%) developed headaches, with 16 (76%) experiencing persistent headaches longer than 3 months after exposure (Table 3).

In the persistent stage, headaches were reported to be exacerbated or associated with cognitive tasks (n=13,62%), rehabilitative therapies (n=11,52%), photophobia (n=9,43%), and phonophobia (n=6,29%). Patients with antecedent headaches were able to differentiate the character of these headaches from that of their standard headaches. Headaches were generally reported to improve with medications (n=12,57%) and appropriate therapies for oculomotor and vestibular impairments (eTable 11 in the Supplement).

#### Imaging

MRI neuroimaging was obtained in all 21 patients. Most patients had conventional imaging findings, which were within normal limits, at most showing a few small nonspecific T2-bright foci in the white matter (n =9, 43%). There were 3 patients with multiple T2-bright white matter foci, which were more than expected for age, 2 mild in degree, and 1 with moderate changes. The pattern of conventional imaging findings in these cases was nonspecific with regard to the exposure/insult experienced, and the findings could perhaps be attributed to other preexisting disease processes or risk factors. Advanced structural and functional neuroimaging studies are ongoing.

#### Rehabilitation and Return to Work

Individualized rehabilitation programs were developed, which included combinations of neuro-optometric rehabilitation (n = 14, 67%), vestibular physical therapy (n = 17, 81%), and cognitive rehabilitation with speech pathology and/or occupational therapy (n = 13, 62%). The most symptomatic patients (n = 14, 67%) requiring multiple therapies did not return to work.

Vestibular physical therapy sessions focused on balance retraining, static and dynamic posture control with substitution via visual and somatosensory systems, gaze stabilization exercises, habituation, smooth pursuits, and saccadic eye movement exercises. Patients treated with vestibular rehabilitation have demonstrated a positive response with improved balance and reduction of disequilibrium.

Formal neuro-optometric rehabilitation, including manipulation of disparity vergence and accommodative amplitude and latency, has been used to treat ocular motor deficits. Rehabilitation for abnormal smooth pursuit and saccadic dysfunction was coordinated between neuro-optometric rehabilitation, vestibular physical therapy, and occupational therapy. Vestibular physical therapy focused on oculomotor function with the body in motion and occupational therapy emphasized functional tasks such as visual scanning in a simulated work environment.

Following comprehensive neuropsychological testing, a formal cognitive rehabilitation program was initiated in the form of occupational therapy and/or speech therapy.

Early return to work with intensive cognitive loading led to an exacerbation of neurocognitive, vestibular, and visual

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symptoms in 7 individuals (33%). Individualized return to work plans were designed to reintegrate individuals using a stepwise process and appropriate work modifications.

#### Discussion

Preliminary findings are described of a case series of individuals stationed in Havana, Cuba, nearly all of whom reported directional audible and/or sensory phenomena that was followed by the development of a consistent cluster of neurological signs and symptoms. The clinical manifestations may represent a novel clinical entity, which appears to have resulted from a widespread brain network dysfunction (ie, cognitive, oculomotor, and central vestibular) as seen in mild traumatic brain injury, or concussion, 30 as well as injury to the peripheral vestibular system in some cases. It is currently unclear if or how the noise is related to the reported symptoms. In particular, sound in the audible range (20 Hz-20 000 Hz) is not known to cause persistent injury to the central nervous system and therefore the described sounds may have been associated with another form of exposure.

Cognitive symptoms, including difficulty remembering (n=16, 76%) and feeling cognitively slowed (n=14, 67%) were the most problematic for individuals in this series more than 3 months after exposure, with neuropsychological testing identifying impairments in at least 1 cognitive domain in all 6 patients who completed neuropsychological evaluation to date (eTables 2, 3, and 4 in the Supplement). Cognitive difficulties interfered with these patients' ability to multitask, process information quickly with accurate recall, solve problems, and perform rapid decision making. Compared with vestibular and oculomotor impairments, cognitive impairments are often the slowest to improve following acquired brain injury, which was observed in this series. Therefore, extended cognitive rehabilitation with emphasis on return to work was used. In addition, it is not uncommon for patients with neurological injury resulting in cognitive impairment to have mood disturbances such as depression, anxiety, and/or posttraumatic stress disorder. Mood dysfunction can directly result from acquired brain injury or develop in response to the precipitating event and novel deficits.31-33

The presence of subjective neurological symptoms presenting in a cohesive community has raised concerns for collective delusional disorders, including mass psychogenic illness. However, neurological examination and cognitive screens did not reveal evidence of malingering, and objective testing and behavioral observations during cognitive testing indicated high levels of effort and motivation. Several of the objective manifestations consistently found in this cohort (such as oculomotor and vestibular testing abnormalities) could not have been consciously or unconsciously manipulated. Furthermore, mass psychogenic illness is often associated with transient, benign symptoms with rapid onset and recovery often beginning with older individuals. 34,35 In contrast, the Havana cohort experienced persisting disability of a significant nature and are broadly distributed in age. Rather than seeking time away from the workplace, the patients were largely determined to continue to work or return to full duty, even when encouraged by health care professionals to take sick leave.

While not systematically excluded, viral etiologies, chemical etiologies, or both associated with acute onset of persistent neurological impairment and peripheral vestibulopathy with the directional nature of exposure descriptions are not readily apparent. No other manifestations of viral illness, such as preceding fever, were identified. It is unlikely a chemical agent could produce these neurological manifestations in the absence of other organ involvement, particularly given that some individuals developed symptoms within 24 hours of arriving in Havana.

There are important considerations in this investigation. In particular, the anatomic substrates causing the symptoms have not yet been identified. This may represent a significant challenge because even the designation of "concussion," is not yet a true diagnosis, as no definitions include the underlying cause. Nonetheless, there is an emerging consensus that concussion, or mild traumatic brain injury, is a type of brain network disorder, based on classic symptoms (eg, slowed processing speed and memory dysfunction) as well as changes in the white matter tracts and consecutive connectivity, as detected with advanced neuroimaging studies.30,36

Beyond the absence of blunt head trauma, there were additional notable differences between the manifestations observed in the Havana cohort and characteristic acute and persistent symptoms of concussion. For example, individuals experienced unilateral ear pain and tinnitus after exposure, and some were later detected to have a unilateral peripheral vestibulopathy (along with central vestibular dysfunction), a finding uncommon in concussion. Further, studies have reported that while most individuals following concussion have a relatively rapid full recovery, at least 15% are thought to experience characteristic persisting symptoms. 37,38 In contrast to classic concussions, most patients referred following suspected exposure in Havana exhibited significant impairment that persisted for months with no significant improvement in multiple cases until rehabilitation was initiated.

For practicing clinicians, if a patient presents reporting a similar potential exposure and symptoms similar to those observed in mild traumatic brain injury, in addition to a thorough history, objective evaluation should include screening assessments of vestibular, oculomotor, and cognitive functioning. Based on findings of this assessment, appropriate referrals to subspecialists should be considered including neurorehabilitation physiatry, vestibular physical therapy, neuro-optometry, neuropsychology, and audiology.

#### Limitations

This study has several limitations. First, due to the sensitive nature of this publication, certain details typically reported in a case series of exposure were omitted, including specifics about geography, relationships between individuals, and individual demographics. Second, because these patients' first evaluation was elsewhere, each patient did not undergo each of the tests described. In particular, neuropsychological characterization was incomplete at the time of publication.

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Preliminary results were presented given the importance and strong public interest in this case series. Third, the rehabilitative course of this Havana cohort may not be representative because this represents a referral population. There may be additional individuals exposed while in Havana, Cuba, who have not been identified due to subtler manifestations that either resolved spontaneously or did not prompt presentation for medical treatment. Therefore, the actual number of individuals exposed is unknown, and the relative "dose" of exposure that causes acute and chronic symptoms remains unclear.

#### Conclusions

In this preliminary report of a retrospective case series, persistent cognitive, vestibular, and oculomotor dysfunction, as well as sleep impairment and headaches, were observed among US government personnel in Havana, Cuba, associated with reports of directional audible and/or sensory phenomena of unclear origin. These individuals appeared to have sustained injury to widespread brain networks without an associated history of head trauma.

#### ARTICLE INFORMATION

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Author Affiliations: Department of Physical Medicine and Rehabilitation, University of Pennsylvania, Perelman School of Medicine Philadelphia (Swanson, Hampton, Biester); Center for Brain Injury and Repair, University of Pennsylvania, Philadelphia (Swanson, Hampton Green-McKenzie, Diaz-Arrastia, Grady, Verma, Biester, Duda, Wolf, Smith): Division of Occupational and Environmental Medione Department of Emergency Medicine, Perelman School of Medicine, University of Pennsylvania, Philadelphia (Green-McKenzie); Department of Neurology, University of Pennsylvania, Perelman School of Medicine, Philadelphia (Diaz-Arrastia); Department oil Neurosurgery. University of Pennsylvania, Perelman School of Medicine, Philadelphia (Grady, Smkh): Department of Radiology, University of Pennsylvania, Perelman School of Medicine, Philacelphia (Verma, Wolf): Penn Therapy & Fitness. Good Shepherd Penn Partners. University of Pennsylvania, Philadelphia (Duda).

Author Contributions: Drs Smith and Swanson had full access to all of the data in the study and take responsibility for the integrity of the data and the accuracy of the data analysis

Concept and design: Swanson, Hampton, Smith. Acquisition, analysis, or interpretation of data: All authors.

Drafting of the manuscript: Swanson, Hampton, Biester, Duda, Smith

Critical revision of the manuscript for important intellectual content; All authors.

Statistical analysis: Swanson, Hampton, Smith, Administrative, technical, or material support, All authors.

Supervision: Swanson, Smith.

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From:

Moundalexis, Athena M

Sent:

4 Apr 2018 17:23:49 +0000

To:

David Brody

Cc:

Tabak, Lawrence (NIH/OD) [E]; Harrison, Brian (HHS/IOS); Gilman, James (NIH/CC/OD) [E];Gordon, Joshua (NIH/NIMH) [E];Koroshetz, Walter (NIH/NINDS) [E];Volkow, Nora (NIH/NIDA) [E]; Johnson, Alfred (NIH/OD) [E]; Simon, Dina (NIH/OD) [C]; Munoz, Mark L; Rosenfarb,

Charles H

Subject:

RE: Setting up a time to meet

Thanks.

#### Official

#### UNCLASSIFIED

From: David Brody [mailto:david.brody@usuhs.edu]

Sent: Wednesday, April 04, 2018 1:22 PM

To: Moundalexis, Athena M

Cc: Tabak, Lawrence (NIH/OD) [E]; Harrison, Brian (HHS/IOS); Gilman, James (NIH/CC/OD) [E]; Gordon, Joshua (NIH/NIMH) [E]; Koroshetz, Walter (NIH/NINDS) [E]; Volkow, Nora (NIH/NIDA) [E]; Johnson, Alfred (NIH/OD) [E]; Simon, Dina (NIH/OD) [C]; Munoz, Mark L; Rosenfarb, Charles H Subject: Re: Setting up a time to meet

#### All

I'm happy to help to the best of my ability.

I have some awareness of this situation from a previous State Dept meeting at Usuhs earlier this year.

Best.

Db.

#### Sent from my Phone

On Apr 4, 2018, at 12:31 PM, Moundalexis, Athena M < Moundalexis AM@state.gov > wrote:

Hi all.

While we are still working on the timing, attached please find some read-ahead materials: For location; would you like us to come to NIH?

Dr. Brody,

We would welcome your participation.

Thanks.

Athena

Official

UNCLASSIFIED

From:

Koroshetz, Walter (NIH/NINDS) [E]

Sent:

4 Apr 2018 23:08:56 +0000

To:

Volkow, Nora (NIH/NIDA) [E]; Tabak, Lawrence (NIH/OD) [E]; Moundalexis,

Athena M

Cc:

Harrison, Brian (HHS/IOS); Gilman, James (NIH/CC/OD) [E]; Gordon, Joshua (NIH/NIMH) [E];Carly Larkin;David Brody;Johnson, Alfred (NIH/OD) [E];Simon, Dina (NIH/OD) [C];david.brody@usuhs.edu;Munoz, Mark L;Rosenfarb, Charles H;Schulke, Hilda (NIH/NIDA) [E]

Subject:

RE: Setting up a time to meet

I have my Board of Scientific Counselors reporting to me that morning at 8 in downtown Bethesda. Usually done by 10:30. So might be a little late.

Best,

Walter

Walter J. Koroshetz, M.D.

Director, National Institute of Neurological Disorders and Stroke

From: Volkow, Nora (NIH/NIDA) [E]

Sent: Wednesday, April 04, 2018 7:04 PM

To: Tabak, Lawrence (NIH/OD) [E] <Lawrence.Tabak@nih.gov>; Moundalexis, Athena M <MoundalexisAM@state.gov>

Cc: Harrison, Brian (HHS/IOS) <Brian.Harrison@hhs.gov>; Gilman, James (NIH/CC/OD) [E] <james.gilman@nih.gov>; Gordon, Joshua (NIH/NIMH) [E] <joshua.gordon@nih.gov>; Koroshetz,

Walter (NIH/NINDS) [E] <koroshetzw@ninds.nih.gov>; Carly Larkin <carly.larkin.ctr@usuhs.edu>; David Brody <david.brody@usuhs.edu>; Johnson, Alfred (NIH/OD) [E] <JohnsoA1@mail.nih.gov>; Simon,

Dina (NIH/OD) [C] <dina.simon@nih.gov>; david.brody@usuhs.edu; Munoz, Mark L

<MunozML@state.gov>; Rosenfarb, Charles H <rosenfarbch@state.gov>; Schulke, Hilda (NIH/NIDA) [E] <hilda.schulke@nih.gov>

Subject: Re: Setting up a time to meet

#### This time work for me nora

From: "Tabak, Lawrence (NIH/OD) [E]" < lawrence.tabak@nih.gov>

Date: Wednesday, April 4, 2018 at 5:08 PM

To: "Moundalexis, Athena M" < Moundalexis AM@state.gov>

Cc: "Harrison, Brian (HHS/IOS)" < Brian.Harrison@hhs.gov >, "Gilman, James (NIH/CC/OD) [E]" <james.gilman@nih.gov>, Joshua Gordon <joshua.gordon@nih.gov>, Walter Koroshetz

<koroshetzw@ninds.nih.gov>, Carly Larkin <carly.larkin.ctr@usuhs.edu>, David Brody

<a href="mailto:david.brody@usuhs.edu">david.brody@usuhs.edu</a>, Nora Volkow <a href="mailto:nvolkow@nida.nih.gov">nvolkow@nida.nih.gov</a>, "Johnson, Alfred (NIH/OD)

[E]" < johnsoa1@mail.nih.gov>, "Simon, Dina (NIH/OD) [C]" < dina.simon@nih.gov>,

"david.brody@usuhs.edu" <david.brody@usuhs.edu>, "Munoz, Mark L"

< MunozML@state.gov>, "Rosenfarb, Charles H" < rosenfarbch@state.gov>

Subject: Re: Setting up a time to meet

Will check and get back to you by tomorrow. Best wishes, Larry

From: "Moundalexis, Athena M" < Moundalexis AM@state.gov>

Date: Wednesday, April 4, 2018 at 5:06 PM

To: "Tabak, Lawrence (NIH/OD) [E]" < lawrence.tabak@nih.gov>

Cc: "Harrison, Brian (HHS/IOS)" < Brian. Harrison@hhs.gov >, "Gilman, James (NIH/CC/OD) [E]"

<james.gilman@nih.gov>, "Gordon, Joshua (NIH/NIMH) [E]" <joshua.gordon@nih.gov>,

"Koroshetz, Walter (NIH/NINDS) [E]" <koroshetzw@ninds.nih.gov>, Carly Larkin

<carly.larkin.ctr@usuhs.edu>, David Brody <david.brody@usuhs.edu>, "Volkow, Nora

(NIH/NIDA) [E]" <nvolkow@nida.nih.gov>, "Johnson, Alfred (NIH/OD) [E]"

<iohnsoa1@mail.nih.gov>, "Simon, Dina (NIH/OD) [C]" <dina.simon@nih.gov>,

"david.brody@usuhs.edu" <david.brody@usuhs.edu>, "Munoz, Mark L"

< MunozML@state.gov>, "Rosenfarb, Charles H" < rosenfarbch@state.gov>

Subject: RE: Setting up a time to meet

Hi,

Would April 17<sup>th</sup> at 10 am work for NIH? This is the earliest date that the content matter experts from (b) (4)<sub>will</sub> be able to come down to NIH, and 10 am would give the (b) (4)

(b) (4)

Thanks all.
Athena Moundalexis
Official
UNCLASSIFIED

From: Moundalexis, Athena M

Sent: Wednesday, April 04, 2018 12:30 PM

To: 'Tabak, Lawrence (NIH/OD) [E]'

Cc: Harrison, Brian (HHS/IOS); Gilman, James (NIH/CC/OD) [E]; Gordon, Joshua (NIH/NIMH) [E]; Koroshetz, Walter (NIH/NINDS) [E]; Volkow, Nora (NIH/NIDA) [E]; Johnson, Alfred (NIH/OD) [E]; Simon, Dina (NIH/OD) [C]; 'david.brody@usuhs.edu'; Munoz, Mark L; Rosenfarb, Charles H (rosenfarbch@state.gov)

Subject: RE: Setting up a time to meet

Hi all.

While we are still working on the timing, attached please find some read-ahead materials. For location, would you like us to come to NIH?

Dr. Brody,

We would welcome your participation.

Thanks.

Athena

#### Official

UNCLASSIFIED

From: Tabak, Lawrence (NIH/OD) [E] [mailto:lawrence.tabak@nih.qov]

Sent: Wednesday, April 04, 2018 8:18 AM

To: Moundalexis, Athena M

Cc: Harrison, Brian (HHS/IOS); Gilman, James (NIH/CC/OD) [E]; Gordon, Joshua (NIH/NIMH) [E]; Koroshetz, Walter (NIH/NINDS) [E]; Volkow, Nora (NIH/NIDA) [E]; Johnson, Alfred (NIH/OD) [E];

Simon, Dina (NIH/OD) [C]

Subject: Setting up a time to meet

Athena,

With this note I am electronically connecting you to Drs. Gilman (<a href="https://www.cc.nih.gov/about/SeniorStaff/james\_gilman.html">https://www.cc.nih.gov/about/SeniorStaff/james\_gilman.html</a>), Gordon (<a href="https://neuroscience.nih.gov/ninds/Faculty/Profile/joshua-gordon.aspx">https://neuroscience.nih.gov/ninds/Faculty/Profile/joshua-gordon.aspx</a>), Koroshetz (<a href="https://www.ninds.nih.gov/About-NINDS/Who-We-Are/Directors-Corner">https://www.ninds.nih.gov/About-NINDS/Who-We-Are/Directors-Corner</a>), and Volkow, (<a href="https://www.drugabuse.gov/about-nida/directors-page">https://www.drugabuse.gov/about-nida/directors-page</a>) each directors of relevant NIH institutes and centers. They also strongly recommend including Dr. David Brody at USUHS, who also conducts research at NIH (<a href="https://www.usuhs.edu/national/faculty/david-brody-md-phd">https://www.usuhs.edu/national/faculty/david-brody-md-phd</a>). They are prepared to meet with you and Charles Ronsefarb as well as any other relevant content experts to be briefed on the situation discussed yesterday.

They have requested read-ahead materials detailing the medical findings so that they may best prepare.

Dina Simon in my office will coordinate with NIH staff if you could let me know dates/times when you team would be available to meet and where you want the meeting held.

Thanks, and best wishes, Larry

Lawrence A. Tabak, DDS, PhD Principal Deputy Director, NIH